

**HELP SEEKING IN ADULTS WITH ANOREXIA:  
WHAT IS THE ROLE OF SIGNIFICANT OTHERS?**

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## **Thesis abstract**

**Background:** The aim of the study was to explore the role of significant others<sup>1</sup> in problem disclosure and help seeking in adults with anorexia. Existing literature on help seeking is predominantly focused on anorexia in children and adolescents (Honey & Halse, 2005; Tierney, 2005; Thomson et al. 2014). Anorexia becomes more chronic the longer it is left untreated, and delays in seeking treatment are associated with poorer recovery outcomes (Ficher, Quadflieg & Hedlund, 2006). Therefore, early intervention is key. This study sought to explore an under researched area and map the territory for future projects.

**Methodology:** Participants were recruited from a carer group in the UK for carers of individuals with an eating disorder and B-eat, a charity that supports individuals in the UK with their eating disorder. Ten individuals self-selected to participate in the study and took part in a one retrospective semi structured interview. Interviews were audio recorded and transcribed verbatim. The data was analysed using thematic analysis, following the guidelines by Braun and Clarke (2006).

**Results:** Six superordinate themes were identified: (1) First Response, (2) Confrontation and Confession/Denial, (3) Stepping In, (4) "Stepping Back", (5) Care Context and (6) Flexible and Persistent Approach.

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<sup>1</sup> The term "significant other" has been used in this study to denote someone who views themselves as having an important place in the person's life, but does not presuppose closeness to the person. Other terms commonly used in the literature include "close other" (Shoen et al. 2011) or "carer" (Grover et al. 2011) however each term was considered less suitable for this research. "Close other" implies emotional closeness where there maybe none and "carer" implies the person is offering care, which might not be the case.

The themes describe a sequential process over time. Many participants reported that they confronted the person with anorexia about their eating or behaviours and for the majority this led to a confession of a problem. Participants encouraged the person to go the GP as the first port of call, but this did not always lead to a referral for treatment. This seemed to create a new role for participants and they accessed a range of resources to educate themselves to help them to understand what to do. The types of support offered by participants (informational, practical and emotional) were found to match onto an existing theory of social support (Cohen & Wills, 1985). Participants reported that more direct and persuasive approaches were unhelpful and over time they reporting stepping back in their approach. Participants' reports of the care system that they encountered was that it was poor. Most participants reported that the person with anorexia sought help and it was common that they dropped out before they had completed it. Use of self-care techniques prevented participants from being stuck in unhelpful patterns.

Discussion: This study makes novel contributions to the literature in finding that participants educated themselves in trying to encourage the person with anorexia to seek help and the finding of stepping back. Participants' first responses to changes in the person's behaviour support existing studies, as does the finding that people with an eating disorder will disclose their problem to someone close to them. The study findings indicate that better early detection of anorexia in primary care is needed. Furthermore, significant others could be supported to offer the different types of support identified in this study and encouraged to step back earlier in their approach. As self-care techniques were found to be useful, significant others could be encouraged to use these earlier.

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Thank you to my parents for always believing in and supporting me, and to Pete, for your love and support throughout.

## **Statement of Contribution**

Project design: Samantha Cox (with supervision from Mike Rennoldson and Anna Tickle).

Applying for ethical approval: Samantha Cox (with supervision from Mike Rennoldson).

Writing the review of the literature: Samantha Cox (with supervision from Mike Rennoldson).

Recruiting participants: Samantha Cox made contact with services and websites for carers of those with anorexia and/or an eating disorder to discuss support with recruitment. Samantha Cox went to a local carer group to discuss the research informally and information sheets were left with clinicians at the service.

A clinician from an eating disorder charity advertised the study advertisement in their service. Beat the charity, and another website put a link to the study on their website. Beat sent out a tweet to advertise the study. Finally, the leader of a carers group circulated the study advertisement via email to members.

Data collection: All interviews were conducted by Samantha Cox.

Interviews were transcribed by Samantha Cox and Helen Smith (professional transcriber).

Data analysis was conducted by Samantha Cox (with supervision from Mike Rennoldson and Anna Tickle).

Write up: Samantha Cox (with supervision from Mike Rennoldson and Anna Tickle). Mike Rennoldson, Anna Tickle and Faye Harrison Yuill offered feedback on early drafts.

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## **Systematic Review**



**First person accounts of recovery from anorexia nervosa:  
A meta-synthesis of qualitative research\***

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## ABSTRACT

**Objective:** To report a meta-synthesis review of qualitative research studies exploring the first person accounts of recovery from anorexia.

**Methods:** The meta-synthesis followed four procedural steps: 1) Comprehensive search, 2) Data extraction: General characteristics and key findings 3) Quality appraisal 4) Synthesis of findings. 18 studies met the inclusion criteria; first personal accounts from anorexia; qualitative studies; peer reviewed and written in English. A secondary thematic analysis method was used to synthesise study findings and identify key themes.

**Results:** For these individuals, the process of recovery consisted of four phases; Fear/frustration, letting others in, self-appraisal and living alongside anorexia. Within these phases, nine themes were identified.

**Discussion:** For the individuals in these studies recovery from anorexia is experienced an ongoing journey rather than an end point. It is acknowledged that the themes link with the more general principles of recovery. It is suggested that clinicians assessing the individual's interpersonal environment and treatment should incorporate recovery principles.

**Keywords:** anorexia nervosa, patient perspective, recovery, qualitative.

## INTRODUCTION

Anorexia nervosa is a physically, psychologically and socially disabling condition<sup>1</sup> with a lifetime prevalence rate of 0.9-2.2% in women<sup>2</sup> and associated with a high mortality rate.<sup>3</sup> Full recovery from anorexia is poor<sup>4</sup> and there are currently no universally effective treatments for adults.<sup>5</sup>

The process of recovery in anorexia is poorly understood and not clearly defined.<sup>6</sup> Greater understanding of the process of recovery from this potentially fatal disorder is important.<sup>7</sup> Exploring client's definitions of recovery could be used to assess treatment outcomes and may lead to a focus on outcomes from the patient perspectives.<sup>8</sup>

Across studies, definitions of recovery and reported recovery rates are inconsistent.<sup>9</sup> The majority of our current knowledge comes from researchers who objectively define recovery in terms of behavioural outcomes; weight restoration, symptom absence and improved score on psychometric measures.<sup>10</sup> From a clinical perspective, recovery is defined as the individual no longer losing weight and a reduction in anorexic behaviours.<sup>11</sup> Ten percent of patients reached full recovery, defined by being asymptomatic for at least 8 consecutive weeks at one year follow up post treatment.<sup>12</sup> In another study, 50% of individuals were reported as recovered, based on weight restoration alone.<sup>13</sup> Based on weight and menstrual regularity, 75% of patients reportedly achieved recovery.<sup>14</sup>

Debate has also emerged around whether full recovery is even possible, with 50% of participants stating full recovery is impossible.<sup>15</sup> Weight gain remains the primary factor in assessing recovery; followed by the absence or presence of disordered eating behaviours. However, Fenning, Fenning and Roe<sup>16</sup> found that when patients returned to their previous weights before anorexia, they retained disturbed attitudes towards food and body size.

Whilst these quantitative studies are useful, there is increasing recognition that recovery processes are complex and difficult to measure and may be best captured by focusing on the patient's subjective perspective via qualitative methods.<sup>17</sup> These methods are able to facilitate a richer understanding of the constructs involved in the process of recovery that might be more difficult to capture with traditional quantitative methods.<sup>18</sup>

First person accounts can add to the understanding of recovery by giving attention to the words of those that have recovered from anorexia.<sup>19</sup> In qualitative research there has been a flourishing interest in first person accounts and it seems the right time to bring these accounts together. Meta synthesis is a method that brings together qualitative studies to enhance their contribution to the development of more formalized knowledge and to make findings more available for application in practice.<sup>20</sup> A qualitative meta-synthesis involves a "dynamic and iterative process of thinking, interpreting, creating, theorizing and reflecting" (Paterson, Thorne, Canam, Jillings<sup>21(p112)</sup> with the purpose to "deconstruct current ideas about a phenomenon and to come to a clearer, deeper, "more socially responsible" theoretical understanding" (Paterson et al.,<sup>21(p111)</sup>.

This review aims to synthesise the findings from multiple studies in order to achieve an overarching understanding of first person accounts of recovery of people with anorexia nervosa.

## **METHODS**

### **Systematic literature search**

#### Data sources

Four methods of identifying primary studies were utilized. Firstly, a systematic search was conducted on five electronic databases: EMBASE, Medline, PsycINFO, CINAHL and International Bibliography of the Social Sciences (IBSS) in week one of July 2013. Together these databases represent the disciplines of medicine, nursing and social sciences. They cover a wide date span and include large numbers of journals.

A list of keywords and MeSH terms were generated and combined to identify studies relating to three specific parameters: 1) terms relating to anorexia 2) terms relating to personal account and 3) terms relating to recovery. Where possible, subject headings were selected and exploded in order to retrieve articles where different authors might have used different terminology for the same concept. Where subject headings were not available, free-text search terms were used. Search terms varied slightly dependant on the database terminology and were adapted accordingly. See Appendix A for the full search strategy for each database with Boolean operators. Use of the full range of terms on database IBSS remitted an unfeasible number of studies. Experimentation with different appropriate terms found that using "recovery" and "anorexia" returned the most relevant and fewest irrelevant papers.

#### Inclusion and exclusion criteria

The title, abstract and full text of papers were examined against the following pre-specified inclusion and exclusion criteria outlined below:

#### Inclusion criteria:

- First person accounts of recovery from anorexia.

- Studies on recovery from eating disorders, but only the data about recovery from anorexia would be extracted and included for this review.
- Used a qualitative method of data collection and analysis. Studies which used a mixed-methods design were included, but only the qualitative data would be extracted for the objective of this review.
- To control for quality, only peer-reviewed journal articles were included.
- For reasons of practicality, only English language studies were considered.

#### Studies were excluded if:

- They were about recovery from eating disorders, but did not distinguish anorexia when reporting the study findings.
- No date restriction was applied other than the start date of the databases.

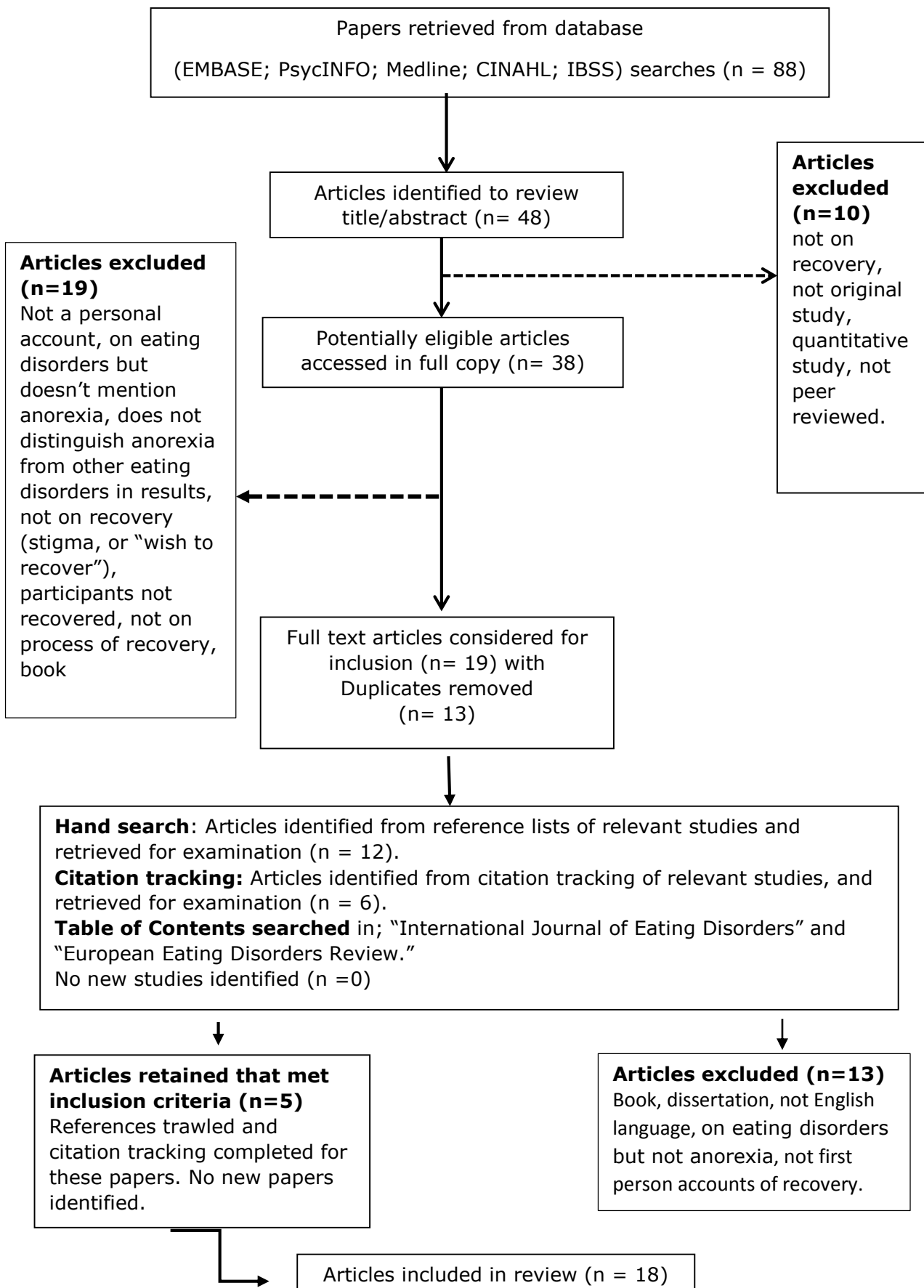
#### Study Selection

All searched title and abstracts were screened for relevance according to the inclusion and exclusion criteria. Where there was not enough information from the title or abstract (or where the abstract was not available), full text versions were obtained. The majority of citations were excluded at this stage because; papers were not on recovery, the study was on eating disorders but it was not possible to extrapolate the findings on anorexia or the paper was not peer reviewed.

The remaining papers were obtained in full texts via Athens and interlibrary loan and examined against the inclusion and exclusion criteria. Papers where it was unclear if they met the inclusion criteria were discussed with another researcher.

As a final step, of the (13) papers included in the review; reference list trawling, citation tracking and hand searching the Table of Contents of, "International Journal of eating Disorder" and "European Eating Disorders" Journal, provided an additional search to identify any further potentially eligible studies. Any papers obtained through these additional search methods were subjected to the same criteria check as the original studies. This method identified five relevant papers. Reference list trawling and citation tracking of these five articles identified no new potential studies. A quorum diagram in Figure 1. Illustrates this process of retrieving relevant studies.

Figure 1. Flowchart for identifying relevant studies.





A total of thirteen articles were included from the database searches and five additional articles were identified through reference list trawling and citation tracking. Eighteen articles were therefore included in the final review.

## **Data Extraction**

### General Characteristics and Key Findings

For studies meeting the full inclusion criteria, the following information was abstracted; study aims, sample, how the study defined recovery to select participants, data collection method, data analysis and key findings. The coding frame was based on that used in a previous qualitative synthesis.<sup>22</sup>

### Quality Appraisal

The purpose of the appraisal is to evaluate them for quality. The Critical Appraisal Skills Program (CASP)<sup>23</sup> provides a standardised checklist for appraising qualitative studies using meta-synthesis<sup>24</sup> It consists of 10 questions: Two for screening out inapplicable studies and eight about the research design, data collection and analyses, ethics, reflexivity, and implications of qualitative studies. (See Appendix B for the checklist).

A three-point rating system developed by Feder et al.<sup>24</sup> was used and a score was calculated for each article based on the CASP's eight questions. A weak score of one point, was assigned to articles that offered little justification or explanation for a particular issue. A moderate score (two points) was given to articles that addressed the issue but did not fully elaborate on it. A strong score of three points, was assigned to articles that extensively justified and explained the issue at hand. This study included an additional score of zero, where the article had not met the criteria at all. A score was calculated for all eight questions and then totalled, with a maximum score of 24.

Often these screening tools allow the researcher to eliminate poor quality studies. However, a priori decision was made that every paper meeting the basic criteria would be included in the final analysis because some papers that did not score well in the quality assessment, could still contribute something of value. The synthesis was however “weighted” towards studies that scored more highly.

### Synthesis of findings

Various different methods can be used to synthesise qualitative research including; meta-ethnography,<sup>25</sup> meta-study,<sup>21</sup> critical interpretative synthesis<sup>26</sup> and meta-synthesis.<sup>27</sup> This review uses an inductive secondary thematic analysis approach<sup>28</sup> which allows an interpretative synthesis to be conducted, whilst allowing the researcher to remain close to the primary data. Other reviews report successfully achieving this balance with this method.<sup>28</sup>

Although substantial papers, four studies<sup>17,19,35-36</sup> were excluded from the analytic task because they were from different disciplinary backgrounds and more empirical in their findings than the other papers. It was judged that they could not be synthesised, given the method of analysis for this review. Included studies were read independently and key themes were extracted and grouped together. The themes were grouped into four overall phases that represented the process of recovery for these individuals.

## **RESULTS**

The general characteristics of the 18 reviewed studies and the quality assessment are presented in Table 1 and Table 2 respectively.

**TABLE 1.**  
**General characteristics and Key Findings.**

Study	Location	Study Aims	Sample Size	Sample characteristics	How was recovery defined for participants in the study?	Data collection method and Data Analysis	Key Findings
Beresin, 1989	America	To describe the process of recovering from anorexia by women who have recovered.	N=13	13 females  Mean age of 29.4 years.  Seven single, three divorced, three married.  All Caucasian	Participants self-defined as recovered. Study measured recovery using three clinical measures plus a 90 minute interview.	<b>Method:</b> Semi-structured interviews, 90 minutes.  <b>Analysis:</b> Not specified	The process of recovering from anorexia is the process of becoming a person. The essential therapeutic agent for change, is the establishment of a relationship. Being empathically understood by another, the anorexic can learn who they are and unravel their maladaptive defences. After "recovery" some anorexic defences remain, but the individual can engage in healthy adult relationships and activities. The notion of "spontaneous recovery" may be misleading.
Bjork, 2012	Sweden & Norway	To describe how former male patients perceive life after recovery from an eating disorder	N=15	15 males.  19-52 years (Mean age 23 years).	Participants had completed treatment for their eating disorder or marked improvement	<b>Method:</b> Semi-structured interviews, 60 minutes.  <b>Analysis:</b> Phenomenographic approach	Two descriptive categories were developed; body acceptance and self-worth. Some perceive recovery as coping with remaining impulses to diet or exercise. Others experienced themselves as totally free from the eating disorder.

**TABLE 1. (Continued)**

Study	Location	Study Aims	Sample Size	Sample characteristics	How was recovery defined for participants in the study?	Data collection method and Data Analysis	Key Findings
Espindola, 2013	Brazil	To elicit and describe factors involved in successful anorexia remission for at least 5 years and post recovery life.	N=15	15 women  Age 22-32 years.  Nine single, four married, two divorced.	Absence of symptoms, which do not meet the DSM-IV criteria and confirmed simultaneously by; the patient's self-report, assistant doctor (blinded) and close relative.	<b>Method:</b> Semi-structured interviews, 90-120 minutes.  <b>Analysis:</b> Grounded Theory (Strauss & Corbin, 1997).	4 core factors involved in remission from anorexia; 1. Motivation to change stimuli (pregnancy, imminence of death) 2. Empowerment/autonomy, 3. Media related factors (internet, TV, journals), 4. Treatment factors.
Federici, 2008	Toronto	To investigate the patients' view of relapse and recovery.	N=15	15 women.  Mean age 26 years.  All Caucasian.	BMI $\geq 19\text{kg/m}^2$ were considered weight recovered	<b>Method:</b> Semi-structured interviews, 120 minutes.  <b>Analysis:</b> Phenomenological Approach.	The study identified 6 themes: Internal motivation to change, recovery as a work in progress, the perceived value of the treatment experience, developing supportive relationships, awareness and tolerance of negative emotion, and self-validation.

**TABLE 1. (Continued)**

Study	Location	Study Aims	Sample Size	Sample characteristics	How was recovery defined for participants in the study?	Data collection method and Data Analysis	Key Findings
Garrett, 1996	Australia	To identify sociological reasons for recovery from anorexia.	N=32	Not stated. Researcher was a member of the sample and had shared experience of anorexia.	Participants self-defined as recovered. 15 identified as recovered. Seven as "still suffering", and 10 as "still recovering".	<p><b>Method:</b> Critical phenomenological method. Semi-structured interviews, 120 minutes.</p> <p><b>Analysis:</b> Described using a detailed coding system. Not specified.</p>	Recovery is an ongoing process. Key elements of recovery involved; abandoning obsession with food and weight; building meaningful lives; believing that they were worthwhile and believing they would never return to self-starvation.
Garrett, 1997	Australia	The study focus was on the process of recovery from anorexia. The study sought for sociological, instead of clinical, reasons for recovery.	N=32	Not stated.	Participants self-defined as recovered. 15 identified themselves as recovered. Seven as "still suffering", and 10 as "still recovering".	<p><b>Method:</b> Autobiographical accounts and semi-structured interviews, 120 minutes.</p> <p><b>Analysis:</b> Not clear.</p>	Anorexia and recovery can be thought of as "negative" and "positive" parts of the same ritual practices, of ongoing initiation into maturity and a consciously fuller way of living, through a symbolic encounter with death.

**TABLE 1. (Continued)**

Study	Location	Study Aims	Sample Size	Sample characteristics	How was recovery defined for participants in the study?	Data collection method and Data Analysis	Key Findings
Granek, 2007	Toronto, Canada.	To examine the subjective experience of anorexia nervosa in interviews with 5 women who have experienced symptoms of the disorder.	N=5	5 female  25-30 years.  One married, two live alone, one with family and two lived with room-mates.	Not experiencing clinically significant distress over eating and self-identified as recovered.	<b>Method:</b> Semi-structured interviews, 90 minutes.  <b>Analysis:</b> Grounded theory method (Glaser & Strauss, 1967).	Individuals had to find new sources of self-worth and new ways to define achievement. It was concluded that anorexia may be largely a relational process that involves a maladaptive desire for self-worth, mediated through control of eating and weight. The role of the media in promoting an ideal of thinness for women was discussed as a factor in the disorder.
Hardin, 2003	America	To analyse through the narratives of young women, the notion of recovery as it is located within social and cultural practices.	N=12	12 female  Aged 19-34 years, Mean age 24.5 years.	Participants self-defined as "recovery" or "recovered".	<b>Method:</b> Poststructuralist: Semi-structured interviews, 2 autobiographical accounts and messages from an anorexia support board bulletin for 5 years.  <b>Analysis:</b> Discourse Analysis	Individuals choosing to stop self-starve are not able to step outside of society's obsession with health, fitness, food and weight. The cultural space they step into after stepping out of self-starvation is not fundamentally different than the space occupied when starving.

TABLE 1. (Continued)

Study	Location	Study Aims	Sample Size	Sample characteristics	How was recovery defined for participants in the study?	Data collection method and Data Analysis	Key Findings
Higbed, 2010	UK	To explore illness perceptions in anorexia using a qualitative design, which focused on personal models of anorexia from the perspective of those experiencing the disorder.	N=13	13 female  Aged between 16 – 53 years. Mean age 26 years.	Participants currently in treatment for anorexia.	<b>Method:</b> Semi-structured interviews.  <b>Analysis:</b> Grounded theory (Charmaz, 2006)	Four overarching themes were identified for these individuals: "Making sense of anorexia", "the relationship between anorexia and the self", "the recovery struggle" and "coping with treatment"
Hsu, 1992	Aberdeen , Scotland and London, UK	To understand the process of recovery from anorexia, from personal accounts.	N=6	6 female.  Ages 34, 35, 36, 37, 39, 39 years.	Participants self-defined as recovered.	<b>Method:</b> Semi-structured interview, 2-3 hours.  <b>Analysis:</b> Not specified.	"Personality strength", "self-confidence", "being ready" and "being understood" were the factors most commonly identified as important for recovery.
Jenkins, 2012	UK, Surrey.	To explore the process of recovery from anorexia from the patient's perspective. To gain insights into what patients believe are the active mechanisms of change for their condition.	N=15	15 women,  Aged 19-49 years. Mean age, 28 years.	Participants self-defined as either "recovered", "always recovering", "semi recovered" or "in recovery"	<b>Method:</b> Semi structured telephone interviews, 40 and 70 minutes.  <b>Analysis:</b> Interpretative, phenomenological analysis (IPA)	Recovery reflects the time when many different components of themselves are no longer divided and this was often facilitated through therapy and close relationships, which enabled them to find non bodily means to express their distress. Therapy should facilitate a sense of becoming "whole again".

**TABLE 1. (Continued)**

Study	Location	Study Aims	Sample Size	Sample characteristics	How was recovery defined for participants in the study?	Data collection method and Data Analysis	Key Findings
Lamoureu, 2005	Canada	To describe the experience of recovery from anorexia from the patient's perspective in a process-orientated manner	N=9	Nine women,  Aged 19-48 years.  Two college students, six were employed and one was unemployed.	Participants self-defined as recovered.	<b>Method:</b> Semi-structured interviews, telephone or face to face 2-3 hours.  <b>Analysis:</b> Grounded theory (Strauss & Corbin, 1998).	Recovery focused on rediscovery and redefinition of the self. The findings support therapies that foster therapeutic alliance, acknowledge readiness for change and promote a sense of autonomy.
Matusek, 2009	America	To present rich, process-orientated stories of recovery drawing on the work supporting spiritual and/or political discourses for achieving recovery.	N=3	3 women.  Ages 24, 46, 57years,  1 in a committed relationship.1 married, 1 divorced	Participants self-defined as recovered.	<b>Method:</b> Semi-structured interviews.  <b>Analysis:</b> Interpretative biographical method	Recovery from an eating disorder, requires attention to the person as a whole, in all their mental, emotional, physical, social and spiritual richness. The core components of these women's stories emerged in the forms of social activism and deepening spiritual commitment.
Nilsson, 2006	Sweden	To identify the most important persons and most valuable recovery factors in recovery from anorexia.	N=68	68 female  Median age 30 years.	Not stated	<b>Method:</b> Semi-structured interviews.  <b>Analysis:</b> Content analysis (Graneheim & Lundman (2004); Kvale (1996).	Those who had recovered described clear turning points in their lives and mentioned, as most important aspects of their recovery; friends, own decisions, activities, treatment, and family.



**TABLE 1. (Continued)**

Study	Location	Study Aims	Sample Size	Sample characteristics	How was recovery defined for participants in the study?	Data collection method and Data Analysis	Key Findings
Riley, 2009	England	To explore the role of online "body talk" in the management, negotiation, and development of eating disorder related identities.	N= 70	All posts by females living in UK, US or Australia predominantly.	Participants self-defined as recovered.	<b>Method:</b> Data collected from two eating disorder forums.  <b>Analysis:</b> Discourse analysis (Potter & Wetherell, 1987).	Three forms of body talk were identified; descriptions of doing something with the body, descriptions of the body, and descriptions of bodily experiences.
Shohet, 2007	America	To explore the narrative processes through which women treated for anorexia reframe their illness and recovery experiences.	N=3	3 women.  Aged between 19-29 years.  Euro-American ethnicity	One participant self-defined as recovered, two as "struggling to recover".	<b>Method:</b> Semi-structured interview conversations, 9 hours total.  <b>Analysis:</b> Narrative analysis.	Recovery from anorexia is not just an outcome to be measured in terms of symptoms but entails a narrative process that links past, present and future visions of the self in relation to others.
Tozzi, 2003	New Zealand	To explore anorexic patients' subjective accounts of the causes of their anorexia and factors that fostered recovery	N=69	69 women.  Mean age at interview, 32.3 years.  46% married.	Recovery was defined as the absence of diagnosis of any eating disorder on the basis of DSM-III-R criteria at the time of the interview and weight stabilisation.  At the time of interview, 10% of participants were defined as not recovered.	<b>Method:</b> Structured interview: The Diagnostic Interview for Genetic Studies; (Frances, 1994) and semi structured interviews.  <b>Analysis:</b> The JMP program (SAS Institute, 1994) and simple statistics.	Most commonly perceived causes of anorexia; dysfunctional families, weight loss and dieting, stressful experiences and perceived pressures. Most common factors contributing to recovery were; supportive relationships, therapy and maturation.

**TABLE 1. (Continued)**

<b>Study</b>	<b>Location</b>	<b>Study Aims</b>	<b>Sample Size</b>	<b>Sample characteristics</b>	<b>How was recovery defined for participants in the study?</b>	<b>Data collection method and Data Analysis</b>	<b>Key Findings</b>
Weaver, 2005	Canada	To explore the perceptions of 12 women who considered themselves recovered or recovering from anorexia.	N=12	12 women.  Aged 14 - 63 years.  White, biracial heritages (one woman French and Aboriginal descent).	Participants self-defined as recovered or recovering.	<b>Method:</b> Semi-structured interviews.  <b>Analysis:</b> Feminist grounded theory.	Recovery from anorexia is an ongoing journey. A self-developmental model was constructed from the findings and recovery was depicted as self-awareness, self-differentiation and self-regulation. Recovery from anorexia is about managing difficult transitions in life.

**TABLE 2. Quality appraisal of studies using CASP criteria**

Study	Question 1 Was there a clear statement of the aims of the researcher?	Question 2 Is a qualitative method appropriate?	Question 3 Was the research design appropriate to address the aims of the research?	Question 4 Was the recruitment strategy appropriate to the aims of the research?	Question 5 Were the data collected in a way that addressed the research issue?
Beresin	3	3	1	2	3
Bjork	3	3	3	2	3
Espindola	3	3	2	2	3
Federici	3	3	2	3	3
*Garrett	3	3	2	3	3
Garrett	3	3	2	0	3
Granek	3	3	1	2	2
Hardin	3	3	3	1	2
Higbed	3	3	3	3	3
Hsu	3	3	1	2	1
Jenkins	3	3	2	2	3
Lamoureux	3	3	3	3	3
Matusek	3	3	2	1	2
Nilsson	3	3	1	2	3
Riley	3	3	3	3	3
Shohet	2	3	3	0	1
Tozzi	3	3	1	2	2
Weaver	3	3	3	2	3

\*1996

**TABLE 2 (continued)**

Study Reference	Question 6 Has the relationship between researcher and participants been adequately considered?	Question 7 Have ethical issues been taken into consideration?	Question 8 Was the data analysis sufficiently rigorous?	Question 9 Is there a clear statement of findings?	Question 10 How valuable is the research?	Overall CASP score
Beresin	1	0	0	2	1	10
Bjork	1	1	3	3	2	19
Espindola	2	3	2	3	3	20
Federici	2	3	3	3	3	22
*Garrett	3	0	1	3	2	18
Garrett	2	0	1	3	2	14
Granek	3	0	3	2	3	16
Hardin	0	0	1	1	2	11
Higbed	3	3	3	3	3	24
Hsu	1	0	0	2	1	8
Jenkins	2	2	2	2	3	18
Lamoureux	1	2	2	2	3	19
Matusek	1	2	1	2	3	14
Nilsson	1	2	1	1	2	13
Riley	0	3	2	2	2	18
Shohet	0	0	2	2	1	9
Tozzi	0	0	2	2	1	10
Weaver	0	2	2	3	3	18

\*1996

**Key:****Score 0** = no justification or explanation.**Score 1 (weak)** = little justification or explanation.**Score 2 (moderate)**= study addressed the issue but did not fully elaborate on it.**Score 3 (strong)**= article extensively justified and explained the criteria.

## RESULTS

### Sample

Together, the 18 studies reported on data, from a total of 402 adults who had recovered from anorexia. Although it is speculated that two studies used the same sample.<sup>17,19</sup> Where reported, the mean age of participants was 27 years. Full demographic information (age, gender marital status, ethnicity, occupation) was not reported for all studies. Eight studies only reported age and gender of participants<sup>6-9,18,29,31,34</sup> and only four reported ethnicity.<sup>10,30,32,36</sup> More information would have been useful to see if certain characteristics were being overrepresented and help the reader to situate the sample and provide context to the data.

In the majority of studies the participants were all female.<sup>15,18,30-34</sup> In three studies, the gender of the participant was not stated<sup>17,19,35</sup> and in one study, participants were purposively all male<sup>29</sup>. Ninety-five percent of diagnosable cases of eating disorders are believed to occur in women,<sup>9</sup> which might explain the high number of female participants.

Participants either self-defined as recovered<sup>7-9,17,19,32-33,35-36</sup> or it was measured objectively (using a psychometric measure, weight reaching safe BMI, or by symptom absence according to DSM criteria).<sup>5,18,29-30</sup> Two studies used both.<sup>15,31</sup> In one study this information was not provided.<sup>34</sup> Having a heterogeneous sample and range of definitions of recovery, reflects the aim of this review; to try and conceptualise the term. In one study, participants spoke about recovery as they hoped that it would be,<sup>6</sup> some after 12-14 months,<sup>18,31</sup> and some up to 24 years later.<sup>32</sup>

## **Location**

Qualitative studies seek heterogeneous samples to provide diversity. These studies were conducted in a variety of locations including; America, UK, Sweden, Canada and Australia. Although this reduces the impact of overrepresentation of a group from one geographical area, all of these countries are advanced capitalist societies.

## **Ethical consideration**

Consideration of ethical issues was evident in only nine of the 18 studies. This was most likely to be an acknowledgement that ethical approval had been established.<sup>5-6, 8, 10,18,29-30,33,35</sup> Many articles considered issues of consent<sup>5-6,8,10,18, 32-34</sup> and some of anonymity.<sup>6,8,15,35</sup> Only one study reported consideration of the effects of taking part on the participants.<sup>6</sup>

## **Sampling**

All participation in these studies was voluntary. Participants were either ex-patients that were written to asking to take part<sup>5-7,18,30,34</sup> or were recruited through community adverts.<sup>8,15,29,32-33</sup>

The majority of studies failed to report how they had reached the number of included participants. Three studies justified their sample size based on reaching theoretical data saturation.<sup>10-29-30</sup> One justified their sample size based on the approach used<sup>29</sup> and one on a practicality basis of those who could attend the interview.<sup>7</sup> Only two studies reported why some people chose to take part.<sup>18,34</sup> It would have been useful if more studies had reported this, so that future research could attempt to capture the underrepresented groups.

## **Data collection method**

All studies collected their data using semi-structured interviews, with the exception of one, who collected data from two eating disorder forums online.<sup>35</sup> This highlights a weakness in the research field, as a wider range of data collection techniques were not drawn upon. The majority of interviews were conducted face to face<sup>5-7,10,17-19,29-31,33-34</sup> One study conducted telephone interviews,<sup>8</sup> one study used both<sup>32</sup> and four studies did not make this clear<sup>9,15,34,36</sup>

The majority of studies failed to adequately justify their reason for choosing their method.<sup>5-7,15,18,29-31,33-34</sup> Four studies reported that researchers kept memos and field notes<sup>6,31-32,35</sup> but only two of these studies stated how these aided data analysis.<sup>6,31</sup> This increased credibility of the study analysis and enhanced transparency of the research process.

The majority of studies made their methods explicit, providing some information about the content of their interview topic guide<sup>5-6,8,15,17-19,29-30,32,34</sup> and were transparent about the role of the person who conducted the interview<sup>6-7,10,15,17-19,29-30,34,36</sup>. Two studies stated how and why they modified their interview schedule during the study.<sup>6,32</sup> Two studies provided a brief overview of the interview topic<sup>7,31</sup> and three studies provided no information on the topic guide at all.<sup>9-10,33</sup> A lack of transparency regarding the interview topic reduces the robustness of the data, making it difficult to situate and interpret results. Nine studies reported using audiotape<sup>5,8,18,29-30,32-34</sup> and nine studies reported that the raw data was then transcribed verbatim.<sup>6,8,18,29-30,31,32-34</sup>

## **Data analysis**

A range of methods were employed including; phenomenological approaches,<sup>8,18,29,32</sup> content analysis,<sup>34</sup> discourse analysis,<sup>9,35</sup> biographical approach,<sup>33</sup> narrative analysis<sup>36</sup> and

grounded theory approaches.<sup>6,10,30-31</sup> Five studies did not clearly specify the data analysis method.<sup>5,7,15,17-19,29-30</sup> Three studies reported that they did not analyse and present all of the interviews that they conducted.<sup>7,33,36</sup> Two studies did not justify why<sup>7,36</sup> and one studied provided a vague rationale.<sup>33</sup>

Only nine studies reported an in-depth description of the analysis process<sup>8,6,10,18,29,31-33,35</sup> and five did not describe the analysis process at all.<sup>7,15,17,19,30</sup> One study stated that the process could be requested from the author.<sup>34</sup> Without a thorough description of the analysis, it was difficult to understand how the themes were derived. This did not affect the ability to synthesise the findings from the studies, but it was not possible to explore the impact of theoretical framework on the interpretation.

The majority of studies did include sufficient original data to support their findings, in the form of direct quotations from participants.<sup>6,8-10,15,18-19,29-32,35</sup> This enabled the subjective experiences of the participants to be represented. Only four studies reported contradictory data<sup>6,8,29,35</sup> which increases confidence in the honesty of their findings.

### **Credibility of analysis**

Eleven studies discussed the credibility of their analysis. Seven studies reported that coding was conducted by multiple analysts and inter-rater reliability was calculated using Cohen's Kappa.<sup>5-6,30,33-34</sup> Five studies reported that their findings were discussed with more than one analyst<sup>6,8,18,29-30</sup> which may enhance credibility of the study and rigor of the findings. In four studies, the researcher made explicit their own role, and potential biases, during formulation of research questions and sample recruitment.<sup>8,15,30,17-19</sup> Although, this was not critically examined in detail. Regarding researcher reflexivity and data analysis, five studies<sup>6,17-19,31</sup> reported that the researcher made effort



to “bracket” their preconceived ideas and assumptions. As no paper reported their epistemological stance, it was difficult to assess whether the credibility checks were consistent with their method and philosophy of science.

### **Findings and Value**

All but one study related their findings back to their original aims and discussed the contribution their study makes to existing knowledge and understandings.<sup>15</sup> Five studies did not report that they had considered how their study findings might have implications on clinical practice<sup>5,15,18-19,36</sup> and only seven studies identified necessary areas for future research.<sup>6,10,18,29-30,32,35</sup>

## Synthesis of Themes

As a result of the inductive thematic analysis a total of nine themes were identified. These can be seen in Table 3. The process of recovery consisted of four sequential phases. The themes and phases are discussed below.

**TABLE 3. Themes and Subthemes**

Study	Theme								
	Fear or Frustration	Letting others in	Self-worth	Self-acceptance	Autonomy	Skills	Recovery is Hard	Anorexia; always a part of you	Relapse Prevention
Beresin	+	+	+	+	+	-	+	+	-
Bjork	-	+	+	+	+	+	+	-	+
Espindola	+	+	+	+	+	+	+	+	+
Federici	+	+	+	+	+	+	+	+	-
*Garrett	-	+	+	+	-	-	-	-	-
Garrett	-	-	-	-	-	+	+	+	+
Granek	-	-	+	-	-	-	+	+	-
Hardin	+	+	-	-	-	-	-	-	-
Higbed	+	+	+	-	-	+	+	+	-
Hsu	+	+	+	+	+	+	+	-	-
Jenkins	+	+	+	+	-	-	-	-	-
Lamoureux	-	+	-	-	+	-	-	-	-
Matusek	+	+	-	-	-	-	-	-	-

\*1996

**TABLE 3. (Continued)**

Study	Theme								
	Fear or Frustration	Letting others in	Self-worth	Self-acceptance	Autonomy	Skills	Recovery is Hard	Anorexia; always a part of you	Relapse Prevention
Nilsson	+	+	+	+	+	+	+	+	-

**Key:** + theme identified in the study

- theme not identified in the study

## **Phase I: Fear or Frustration**

The majority of individuals in these studies described a specific event that served to facilitate reflection and perception of the severity of their anorexia.<sup>5,7-8,10,15,18,30,32-33</sup> This event sparked fear or frustration in the individual, and the response was to start to change and move beyond the illness. This step was always self-determined:

*"This is up to me. I have to do this"* <sup>18(p4)</sup>

For the majority, this awareness arose from an inner personal process, either a frustration of only existing in life<sup>5,7-8,15,18</sup> or becoming frightened of the risk of the "damage" that they had caused to their bodies and the fear of the risk of death:<sup>8,30,32-33</sup>

*"I am bored with this", "I am sick of this"* <sup>15(p120)</sup>

*"Risk of fractures ...or infections"* <sup>30(p2)</sup>

For some it was related to external events, such as pregnancy<sup>7,30</sup> or the affect their eating disorder had on a close family member:<sup>10</sup>

*"It wasn't my body anymore, but my baby's"* <sup>30(p2)</sup>

## **Phase II: "Letting others in" [2]**

A theme in almost all of these studies, was that part of recovery, actively involved trusting another person and letting them into their lives.<sup>5,7,10,15,18,30-34</sup> Individuals described this as a reciprocal process. Learning to trust another was the initial key ingredient. This other person then offered them unconditional acceptance and unwavering support. This dedicated, caring individual (friend, partner, therapist) helped the person to perceive themselves as a worthy, loveable person, and gave them the courage to move forwards, away from the anorexia. This supportive other was described as being non-judgemental, warm, supportive, understanding and accepting:

*"The process of recovering is the process of liking oneself again, this can be done through therapeutic or real relationships, through mutual respect"* <sup>15(p126)</sup>

*"I realised what I look like doesn't matter, it's not the first thing on everyone's agenda...He liked me for me and not the way I looked"* <sup>31(p375)</sup>

### **Phase III: Self-Appraisal**

#### **Self-Worth**

An experience identified in these studies was that recovery involved rediscovering and reclaiming self-identity without the anorexia. Where the anorexic strive for thinness, was about achievement and wanting to feel worthy and appreciated. Recovery was about reconceptualization of what defines a good and worthy person, and realising it is more than a number on the scale.<sup>7-8,10,31-32</sup> Healing began when individuals found new ways of conceptualising their value, by redefining themselves as worthy people through their relationships with others and through exploration of new activities.<sup>32</sup>

*"I'm a student, a friend. I have a social life"* <sup>8(p29)</sup>

It is important to capture that in four studies, some individuals reported that letting go of the anorexia, a part of their self-identity, was a frightening time.<sup>6,10,15,32</sup> Anorexia had been an achievement, and a large and meaningful part of their lives, which gave them a sense of being powerful and in control. Letting this go was scary, because it involved being vulnerable and showing feelings of insecurity in not knowing who they are. In one study, giving up the self-identity of anorexia was described as losing, "protective armour".<sup>15</sup> Again, this is where these individuals found safety in their support networks and became less afraid of being exposed and dependent on anorexia:

*"If I give this up, then who the hell am I?"* 10(p194)

*"It scares me to actually let go of it completely"* 6(p318)

*"I lost a specialness that I thought it gave me"* 15(p124)

### Self-acceptance

For these individuals recovery involved reaching a stage self-acceptance. This meant accepting themselves fully, including their flaws and limitations. They no longer strived to be perfect but accepted themselves as good enough. At this stage individuals became less self-critical and learnt to be more self-compassionate. This was achievable because of the supportive relationship they had experienced: 10,15,18,29-30,32

*"I would quickly go out for a run so that I deserved to eat. I don't think that way anymore"* 29(p464)

*"To accept who you are, you sort of let go in a way...it's a relief not to be so hard on myself"* 29(p465)

*"I've been hard on myself for years. And I'm learning not to be so"* 10(p197)

### Autonomy

Some individuals in these studies had a history of abuse and some reported less traumatic backgrounds, but described having felt overshadowed by others. This theme was about reclaiming personal power and setting the boundaries with others. From experiencing unconditional acceptance by another person, these individuals began to respect and value themselves. They began to assert their own judgements, take control of decisions, and choose what they wanted, rather than perceive what others wanted for them: 10,18,29-30, 31-32,34

*"It's a freedom to make my own decisions...and listen to myself"* 29(p466)

*"This was me reclaiming myself...I actually could speak up for myself and say this was ok or not ok" 32(p177)*

Whilst many spoke of welcoming this autonomy in their life, in one study, an individual spoke of the struggle of letting go of being a child and being cared for:<sup>15</sup>

*"One of the hardest things was throwing away my small clothes" 15(p125)*

*"I wanted to be held like a little girl" 15(p122)*

### Skills

In three studies, individuals experienced recovery as involving learning to acknowledge and tolerate strong negative emotions, and express these feelings in healthier, more adaptive ways, using language as a communication tool, as opposed to their bodies.<sup>8,10,15,18</sup> Individuals learnt to develop skills in self-expression.

### **Phase IV: Living alongside anorexia**

#### Recovery is hard

In six studies, individuals expressed that recovery, was a slow, long and extremely difficult process.<sup>6,8-10,18,32</sup> One study highlighted that when individuals expected it would be difficult they coped better than those who did not:<sup>8</sup>

*"Totally hard work, being on top of it, staying with the meal plan, keep taking risks, being open and honest" 18(p5)*

Some felt that qualities that once played a role in the development of their disorder, were now used to facilitate healthy change, such as patience, determination, self-discipline and perfectionism:<sup>9,18</sup>

*"I work diligently to incorporate fat into my diet. I am careful not to eat too many fruits" 9(p10)*

In three studies, some individuals expressed frustration that treatment focused on weight restoration.<sup>8,18,31</sup> Reaching weight restoration was viewed as merely the first of a succession of steps<sup>18</sup> and of low priority for most individuals.<sup>31</sup> Individuals in two studies reported that underlying issues needed to be addressed, and treatment should focus on cognitions as well as the body and behaviour.<sup>8,31</sup>

### Anorexia, always a part of you

In four studies, individuals spoke about recovery as an ongoing journey<sup>8-9,18,30</sup> and even though they were further along the recovery journey, it was still, "work in progress"<sup>18</sup> which reflected the continuity.

In four studies individuals expressed that anorexia never goes, is always remains a part of them, but that it can be progressively controlled, and over time, starts to lose its power:<sup>6,8-9,15</sup>

*"I don't think for me it will ever go away. I think it will always be present in my life at some point or in some part of me"* <sup>9(p11)</sup>

*"You learn how to control it, over power it and become stronger than it"* <sup>6(p318)</sup>

One study shifted the responsibility of recovery onto society, and discussed recovering in a "non-recovery world",<sup>9</sup> where it is difficult to recover in a culture, obsessed, with diet, food and weight.<sup>9</sup>

In four studies, individuals reported that anorexia still functioned as a defence mechanism, and they continued to respond to periods of acute stress by eating less, exercising more, or returning to previous ways of thinking:<sup>9-10,15,29</sup>

*"During really stressful times, I tend to quote, unquote, forget to eat."* <sup>9(p11)</sup>



Some individuals explained that the anorexia remained with them as they retained a strained relationship with food:

*"I'm aware of what I eat and how much, but not as I was before where I would skip dinner and avoid social gatherings"*

29(p464)

*"I still obsess about food...but I do consider myself recovering definitely because I'm no longer starving myself"* 9(p12)

However, in three studies, some individuals did believe that full recovery was possible, or had even been achieved.<sup>8,15,30</sup> However, they still agreed that it was a slow process, and that remnants of the disorder remained.

### Relapse Prevention

In four studies, individuals discussed strategies to prevent relapse. These included eating regularly, exercising in moderation and not weighing themselves too frequently. Using these strategies became a way of managing the anorexia:<sup>9,29,31</sup>

*"I don't want to have scales so I can minimise the risk of standing on them...the thought that numbers can control my feelings doesn't sound really healthy, so I don't have scales"*

29(p465)

## **DISCUSSION**

### Conceptualising recovery

The aim of this review was to bring together first person accounts of recovery from anorexia, to more clearly understand the process. The findings from these studies illustrate that individuals do not reach an end stage of “recovered”. Rather, the findings illustrate that recovery from anorexia is an ongoing journey. In terms of operationalising the term recovery, from the synthesis of these studies, the recovery process can be best understood in terms of a relational model containing four sequential phases.

The first phase of recovery, is an internal or external event, which triggered fear or frustration in the individual, and led them to want to change. The second phase, was about developing a trusting relationship and being unconditionally accepted by another person. This led to greater self-confidence and self-acceptance. Phase three involved moving away from a self-identity of anorexia, and learning to re-value the self in other ways; becoming more confident in expressing own decisions and choices. The last phase, explained that recovery was a difficult process, and these individuals had to find ways of living with their anorexia. They discussed the strategies that they used to help them cope.

### Implications for practice

Although there are no empirically supported intervention for adults with anorexia, the findings from this study support interventions developed by Fairburn<sup>37</sup> and new approaches being trialled for use with anorexia, such as cognitive remediation and emotion skills training (CREST). This latter approach focuses on techniques to manage emotions, and emotional expression.<sup>38</sup> Learning how to manage emotions in a healthier way, was something that some individuals in these studies identified as an important skill

as part of their recovery. Defining recovery as an ongoing journey has implications for treatment. The findings from these studies advocate that objective measures of recovery, such as weight restoration, should not be the focus of treatment outcomes. All individuals in these studies reported that they found this unhelpful and that when they regained weight, they still felt unrecovered. It seemed for these individuals it was more important to address the unhelpful thoughts and symptoms underlying the anorexic behaviour.

The model of recovery identified in this review might be a more useful way of understanding the process of recovery from anorexia than using a more general and widespread model of behaviour change, such as The Transtheoretical Model of behaviour change.<sup>39</sup> The model identified in this review highlights that it would be unfair to judge someone's recovery progress in terms of them reaching the end stage, rather it highlights that individuals can make significant gains in terms of their personal recovery when they are at phase II or III.

What can be drawn from this review is that unconditional acceptance and support from others cannot be underestimated, in terms of the potential that it has to positively impact on the individual's recovery. In many of the themes identified, support from others was necessary and integral to them making progress in their journey. Therefore, it is recommended that clinicians carefully assess the person's interpersonal environment and that interventions may need to focus on a social level and on social support. The experiences of these individuals illustrate that this support can come from anyone; family, partner or therapist and the individual is ready to change, when the relationship is right. It might be useful to explore whether an intervention might be able to help foster facilitative relationships, or whether this is difficult to try and foster, and occurs more due to chance, and the right relationship at the right time. The

value of supportive others could be something that is incorporated into support groups, where many family members and carers attend.

Expectations about recovery might be important in how the recovery journey is experienced. When individuals expected that recovery would be hard, they appeared to have coped better, than when they were not prepared for setbacks.<sup>8</sup> However, this needs to be managed sensitively as by being too upfront about how difficult the recovery journey might be, may negatively affect people engaging in treatment. One idea is that interventions might chose to incorporate the principles of recovery into the treatment plan, such as fostering hope and helping the individual identify their strengths and values<sup>39</sup> and part of treatment may involve spending more time on the relapse prevention stage.

#### Future areas for research

The above leads onto the discussion of how the four phases of recovery identified in this review, appear to be similar and support the more general principles of recovery in mental health.<sup>39</sup> The principles of recovery perceive recovery as an ongoing journey and the focus is not on eradicating the problem, but defining your values, personal growth and regaining control over your life.<sup>39-40</sup> As the experiences of these individuals fit well with the principles of recovery, more research might be conducted around recovery and how we can best support people in their recovery journey from anorexia.

Some studies were excluded from the analytic task because the nature of analysis produced results that were too theory laden. Future research might chose to focus on this subset of studies and there is the role for a more interpretative analysis. Regarding methods used in these studies, as discussed above, the majority of studies in this review used semi-structured interviews. This is just

one method and it may be time that qualitative research started broadening their methods of data collection.

Future research might also explore in more specific detail some of the concepts that were identified from the findings of these studies. Some concepts discussed above were under elaborated upon, such as recovery is “hard”. Although this was an experience reported by many individuals in these studies, knowing specifically *what* was so difficult about it, was unclear. Further knowledge about this concept would help identify areas where individuals might require more support.

### Limitations

This review has focused specifically on recovery from anorexia. It would be interesting to explore how recovery from restrictive anorexia is, compared to recovery from other eating disorders, such as bulimia or binge eating disorder. The focus purely on recovery from anorexia is a weakness of this study, and it also fails to capture individuals who graduate to other eating disorders and then back to anorexia.

A further limitation of this review was that the interpretation of data was only conducted by one person. If the data had been analysed by another researcher, this may have provided the opportunity to discuss emerging themes, reduce the chances of subjectivity bias and increase the overall credibility of the findings. Once more, due to the large number of included studies in this review, a thematic analysis approach was undertaken, which meant that more theory laden papers were excluded, which is a limitation. Lastly, although the search was fairly comprehensive, all searches are prone to missing papers, and so it is possible that some additional relevant papers might have not been identified in this review.

In conclusion, this review provides an overview, of first person accounts of the recovery process, for these individuals with anorexia. This review, of 18 studies, found that the term recovery, is defined by these individuals as an ongoing journey, and not an end point. The review explained the process of recovery in terms of a relational model, consisting of four, sequential phases. The findings illustrate that trusting another and receiving unconditional acceptance from this person, is completely invaluable, in terms of the impact it has on the recovery progress. This review makes recommendations that clinicians should ensure that they assess the individual's interpersonal environment and that treatment interventions should incorporate the recovery principles.

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## **Appendices**

## **Appendix A: Search Terms**

### **Embase (1980 to 2013 Week 27)**

- 1 exp anorexia/ (38738)
- 2 exp anorexia nervosa/ (14693)
- 3 exp eating disorder/ (33775)
- 4 1 or 2 or 3 (70997)
- 5 exp attitude to health/ (76034)
- 6 exp patient attitude/ (232066)
- 7 exp self report/ (55616)
- 8 exp self concept/ (117989)
- 9 exp personal experience/ (8902)
- 10 personal account.mp. (509)
- 11 subjective account.mp. (15)
- 12 life experience\*.mp. (3465)
- 13 (patient adj3 perception).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword] (2500)
- 14 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 (465027)
- 15 recovery.mp. (351381)
- 16 exp convalescence/ (32495)
- 17 recovery of function.mp. (3128)
- 18 exp disease course/ (1870515)
- 19 disorder recovery.mp. (45)
- 20 disorder course.mp. (33)
- 21 recovery process.mp. (2772)
- 22 exp treatment outcome/ (927742)
- 23 relapse prevention.mp. (2906)
- 24 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 (2808958)
- 25 exp qualitative research/ (19619)
- 26 4 and 14 and 24 and 25 (16)
- 27 limit 26 to english language (15)

### **MEDLINE(R) (1946 to July Week 1 2013)**

- 1 exp Anorexia/ (3972)
- 2 exp Anorexia Nervosa/ (10330)
- 3 exp Eating Disorders/ (21364)
- 4 1 or 2 or 3 (24871)
- 5 exp Self Report/ (6495)
- 6 exp Self Concept/ (70379)
- 7 exp Attitude to Health/ (283475)
- 8 patient\* attitude\*.mp. (1725)
- 9 life experience\*.mp. (2662)
- 10 client\* attitude\*.mp. (74)
- 11 patient perspective.mp. (782)

12 personal account.mp. (418)  
 13 subjective account.mp. (12)  
 14 personal experience.mp. (8174)  
 15 patient\* experience.mp. (6039)  
 16 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 (363567)  
 17 exp "Recovery of Function"/ (29333)  
 18 exp Treatment Outcome/ (624071)  
 19 disease course.mp. (6737)  
 20 relapse prevention.mp. (1899)  
 21 recovery.mp. (295424)  
 22 recovery process.mp. (2189)  
 23 disorder recovery.mp. (35)  
 24 disorder course.mp. (27)  
 25 disease recovery.mp. (113)  
 26 eating disorder recovery.mp. (16)  
 27 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 (897384)  
 28 exp Qualitative Research/ (17524)  
 29 exp Interviews as Topic/ (54087)  
 30 28 or 29 (66116)  
 31 4 and 16 and 27 and 30 (16)  
 32 limit 31 to english language (16)

### **PsycINFO (1806 to July Week 1 2013)**

1 exp Anorexia Nervosa/ (8353)  
 2 exp Eating Disorders/ (21778)  
 3 exp Eating Behavior/ (12305)  
 4 1 or 2 or 3 (30853)  
 5 exp Client Attitudes/ (16282)  
 6 exp Self Concept/ (57085)  
 7 exp Self Report/ (12090)  
 8 exp Life Experiences/ (19069)  
 9 exp Health Attitudes/ (7838)  
 10 exp Self Perception/ (18263)  
 11 patient perception.mp. (309)  
 12 patient\* attitude\*.mp. (1612)  
 13 patient perspective.mp. (316)  
 14 personal account.mp. (969)  
 15 subjective account.mp. (40)  
 16 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 (126708)  
 17 exp "Recovery (Disorders)"/ (8684)  
 18 exp Disease Course/ (8852)  
 19 exp Treatment Outcomes/ (26948)  
 20 exp "Relapse (Disorders)"/ (5066)  
 21 exp Relapse Prevention/ (1832)  
 22 exp "Remission (Disorders)"/ (2433)  
 23 exp Treatment Dropouts/ (2025)

24 exp Treatment Duration/ (6097)  
 25 exp Treatment Termination/ (1769)  
 26 disease recovery.mp. (248)  
 27 eating disorder recovery.mp. (30)  
 28 long term recovery.mp. (303)  
 29 disorder recovery.mp. (197)  
 30 exp Disease Course/ (8852)  
 31 recovery.mp. (43496)  
 32 recovery of function.mp. (722)  
 33 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or  
 28 or 29 or 30  
 or 31 or 32 (92772)  
 34 4 and 16 and 33 (136)  
 35 limit 34 to (english language and ("0700 interview" or "0750 focus  
 group" or  
 1600 qualitative study)) (26)

## **CINAHL**

### **Search terms July 1<sup>st</sup> 2013**

( (MM "Anorexia") OR (MM "Anorexia Nervosa") OR (MM "EATING  
 DISORDERS+" ) ) AND ( (MM "Patient Attitudes") OR (MM  
 "Perception") OR (MM "Attitude to Health") OR (MM "Attitude to  
 Illness") OR (MM "Self Report") OR (MM "Self Concept") OR (MM "Life  
 Experiences") )  
 AND (MM "Recovery").  
 (15)

## **IBSS**

### **Search terms 1<sup>st</sup> July 2013**

anorexia (anywhere) AND  
 recovery (anywhere)  
 limit to: peer reviewed journal (25)

## **Appendix B: Critical Appraisal Tool (CASP)**

### **1. Was there a clear statement of the aims of the research?**

Consider:

- What the goal of the research was
- Why it is important
- Its relevance

### **2. Is the qualitative method appropriate?**

Consider:

- If the research seeks to interpret or illuminate the action and/or subjective experiences of research participants

### **3. Was the research design appropriate to address the aims of the research?**

Consider:

- If the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)

### **4. Was the recruitment strategy appropriate to the aims of the research?**

Consider:

- If the researcher has explained how the participants were selected.
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

### **5. Were the data collected in a way that addressed the research issue**

Consider:

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview)
- If the researcher has justified the methods chosen



- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide?)
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes, etc)
- If the researcher has discussed saturation of the data.

## **6. Has the relationship between researcher and participants been adequately considered?**

Consider whether it is clear:

- if the researcher critically examined their own role, potential bias and influence during:
  - formulation of research questions
  - data collection, including sample recruitment and choice of location.
  - how the researcher responded to events during the study and whether they considered the implications of any changes in the research design?

## **7. Have ethical issues been taken into consideration?**

Consider:

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from ethics committee

## **8. Was the data analysis sufficiently rigorous?**

Consider:

- if there is an in-depth description of the analysis process
- if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- if sufficient data are presented to support the findings
- to what extent contradictory data are taken into account

- whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation.

## **9. Is there a clear statement of findings?**

Consider:

- if the findings are explicit
- if there is adequate discussion of the evidence both for and against the researcher's arguments
- if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- if the findings are discussed in relation to the original research questions

## **10. How valuable is the research?**

Consider:

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research might be used.

## Journal Paper

# **Help seeking in adults with anorexia: What is the role of significant others?\***

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\*For submission to the International Journal of Eating Disorders

## ABSTRACT

**Objective:** This study examined the accounts given by significant others, about their role in facilitating an adult to disclose anorexia and seek help.

**Method:** Ten individuals (parents, partner and friend) who identified themselves as a significant other of an adult with anorexia, self-selected to participate. The study used a qualitative design; participants took part in one semi-structured retrospective interview, which was audio recorded and transcribed verbatim. Transcripts were analysed using thematic analysis.

**Results:** Thematic analysis of the data revealed 4 main themes<sup>2</sup>; (1) first response; (2) confrontation and confession/denial; (3) stepping in and (4) “stepping back”.

**Discussion:** Better detection of early signs of anorexia is needed in primary care. It is recommended that information for carers about what to do to help an adult with anorexia, is made available from one source. Significant others could be supported to step back in their approach earlier. Limitations of the sample and method are discussed. Future research ideas are suggested that include; testing the adequacy of information available for carers and exploring their preference for information, to help match resources to their needs.

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<sup>2</sup> Two further main themes and their subthemes are discussed in the extended paper

## INTRODUCTION

Anorexia nervosa (anorexia) is a physically, psychologically and socially disabling condition<sup>1</sup> with a mortality rate<sup>2</sup> that is amongst the highest of any mental health problem.<sup>3</sup> Estimates of lifetime prevalence range from 0.9-2.2% in women.<sup>4</sup> Whilst the potential condition burden is significant, individuals often do not seek help<sup>5</sup>. Specifically with anorexia, the ego-syntonic nature of the condition can delay help seeking<sup>6</sup> and often individuals will deny having the problem.<sup>7</sup> Trying to encourage someone to seek help for anorexia, might therefore, be difficult. The research reported here investigates how significant others attempted this.

This topic is surprisingly neglected by researchers, even those concerned with other disorders, where help seeking might be similarly problematic. For example, a common clinical problem is requests for help from concerned significant others, seeking ways to support loved ones, who are unmotivated to change alcohol problems.<sup>8</sup> Three approaches are commonly used. Firstly, helping the significant other to learn and accept that they cannot control the person who drinks and offering them a support group. A second approach used is supporting the significant other to confront the person with the problem. A final approach, is to teach the significant other coping skills and strategies that they can then use to help to motivate the person to change. Whilst these might provide possible solutions, research in the area is sparse and outcomes of the interventions are relatively unknown.<sup>8</sup>

Specifically with regards to eating disorders, a qualitative study explored the experiences of twenty carers of individuals with bulimia nervosa (bulimia).<sup>9</sup> One of the experiences that carers reflected on was problem detection and the impact of the detection. Carers reported that the detection of bulimia was a gradual process, with

some reporting that initially they underestimated the severity of the problem. Some carers reported that when they tried to discuss their suspicions with the individual, they were met with denial and defensive responses, which delayed them in identifying the problem.<sup>9</sup> Carers also described their emotional reactions to their suspicions being confirmed, and finding out that the individual had bulimia. Many reported a mixture of powerful negative emotions, including fear and anger, but overall, this experience was characterised by a feeling of hopelessness.<sup>9</sup>

Although the above study focused on carers' experiences with someone with bulimia, parallels can be drawn with anorexia. Both anorexia and bulimia can be secretive conditions and can go undetected for long periods of time. Even if significant others become aware of changes in the person's behaviour, individuals often deny having a problem. Together with the strong emotions the significant other can experience around this time, it can be difficult to confront the person,<sup>9</sup> which can delay help seeking.

Seeking help early for anorexia is important as there is evidence to suggest that treatment is more likely to be successful if the condition is recognised early; before weight loss becomes too severe and prolonged.<sup>10</sup> As the duration of anorexia increases the probability of recovery decreases,<sup>11</sup> and long delays in accessing help are associated with poorer recovery outcomes.<sup>12</sup> It appears that ten years from condition onset is the point at which the probability of recovery begins to decrease.<sup>13</sup> The condition therefore poses the paradox of preventing early intervention by its ego-syntonic nature, yet potentially requiring early intervention to be treated effectively.

#### Help seeking and problem disclosure

There is some support in the literature that individuals do disclose their eating concerns to significant others. A previous study

found that women reported that they would first talk to a friend.<sup>14</sup> Other research on disclosure of eating or weight concerns has found that individuals disclosed their concerns to a friend, but also parents and partners.<sup>15</sup> A study of 71 women (mean age 28 years), found that they first disclosed their eating disorder to their mother or friend.<sup>16</sup> These studies provide evidence that individuals with eating disorders do disclose to close others, but the studies included individuals with a range of eating disorders. The process of problem disclosure might be more complex for individuals with anorexia, where secrecy and denial are common.<sup>17</sup> Being questioned about eating, when it is at an acute stage, can lead to some individuals with anorexia to become defensive and angry.<sup>17</sup> Since accessing help for an eating disorder is dependent on problem acknowledgment and disclosure,<sup>16</sup> more knowledge is required about disclosure in individuals with anorexia.

Whilst it is known that some individuals will disclose their eating problems to a significant other, little is known about how significant others might then be able to facilitate help seeking. Some literature on adults suggests that a “caring confrontation” by a significant other can lead some women with anorexia to seek help.<sup>18</sup> In addition, encouragement from friends and family has been cited as the second most common reason for seeking help for an eating disorder.<sup>19</sup> Comments from others about changes in behaviour or appearance have also been found to prompt help seeking in individuals with bulimia and binge eating.<sup>20</sup> Whilst these studies provide some information about the link between disclosure and help seeking, they do not explore the significant others’ perspective.

### Parents and their children

Exploring help seeking from the perspective of others is an under researched area, and to the authors’ knowledge, studies have only explored the perspectives of parents of adolescents with



anorexia.<sup>21-23</sup> A previous study used interpretative phenomenological analysis (IPA) to explore parents' experiences of problem recognition and deciding to seek help.<sup>23</sup> Early signs of anorexia were understood to be part of adolescent development and initial weight loss was expected to be short-lived. Parents sought professional help for their child when they were unsuccessful in eliciting change themselves.

Other studies have found that parents use their authority to be firm and assertive to try and get their child to comply with treatment.<sup>22-23</sup> Parents also reported using persuasion techniques, such as threatening hospitalisation, being placed under an external legal guardian and verbal encouragement, to try and get their daughters to comply.<sup>22-23</sup> Whilst these studies provide useful insight into how parents might influence their child to seek help, there is no empirical evidence regarding the most effective methods. It is also necessary to remain aware that parents are likely to have more leverage with a child who lives under their roof, and for whom they have a legal responsibility until they are eighteen years old. Influencing adults to seek help for anorexia might be more complicated, because adults are treated differently under the law, and the degree of involvement and reliance on the family is more variable.<sup>24</sup>

There are some wider theories that might be informative when conceptualising help seeking. These include models of behaviour change, such as the Transtheoretical Model<sup>25</sup> which has been applied to many health-change behaviours including obesity, exercise and health screening<sup>26</sup>. It is possible that other models of social influence, traditionally linked with the work on compliance and conformity,<sup>27-28</sup> may also have value. However, whilst helping us to understand what happens at the higher conceptual level, these broader theories make few predictions about specific actions in encouraging help seeking. Given the lack of specific theory and empirical research in this area, there is a clear role for inductive research to develop theory, or at

least help identify, which high level theories might have most relevance to this important clinical issue. There is a dearth of literature about problem disclosure and help seeking in adults with anorexia, particularly from the perspective of others. This study aims to address this gap. Information about strategies used by significant others who were successful in encouraging help seeking might well prove useful to others currently struggling to help an adult in a similar situation. This may lead adults with anorexia to seek help earlier, leading to improved recovery rates. Additionally, the knowledge gained might inform self-help interventions<sup>29</sup> aimed at significant others who are trying to support someone with anorexia.

### Study Aims

This study aims to provide preliminary work in this under researched area to map the territory for future projects. Using a critical realist framework<sup>30</sup> the study aimed to answer the following questions:

How do significant others attempt to facilitate help seeking?

What is the role of significant others in problem disclosure?

## **METHOD**

### Ethical Approval

Ethical approval for the study was gained from the University of Lincoln ethical committee (See Appendix C and D for letter of approval and approved amendments).

### Participants and Recruitment

Eating disorder charities, support groups and online websites for carers of individuals with an eating disorder were approached

about the research. The study was advertised<sup>3</sup> in a local<sup>4</sup> eating disorder service, on websites for carers and circulated via email, to members of a carers group that covered a large geographical area. The main author also discussed the study at a local carer group meeting.

To participate individuals were required to:

- Be a significant other of a male or female adult with anorexia.
- Be aged 18 years or older.
- Have tried to influence an adult (aged 18 years or older) to seek help for anorexia nervosa.
- Be able to communicate verbally in English in a semi-structured interview.

Two individuals that came forward were excluded as they did not meet the criteria; one individual had supported someone with bulimia and the other had only experience of supporting someone under 18 years. Eight participants responded to take part, and two participants were recruited via snowball sampling, through two participants who had already taken part in the study.

Four participants had tried to encourage the person with anorexia pre and post 18 years to seek help. The main author sought to focus the interview post 18 years, but at times in the interview participants moved between ages, so it was not always possible to clarify pre and post 18. (Please see extended paper methodology for further discussion on this).

### Study Procedure

Individuals interested in taking part contacted the researcher by email. After making contact, an information sheet (See Appendix

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<sup>3</sup> See Appendix E for recruitment flyer

<sup>4</sup> Local refers to the East Midlands region.

F) was sent which advised the person to take 72 hours to decide whether to take part. Those who consented then participated in a semi-structured interview, offered via telephone, face to face or Skype. One participant chose a face to face interview whilst nine chose telephone. All interviews were recorded using a digital voice recorder and transcribed verbatim. The interviews typically lasted between 45-90 minutes (average 60 minutes). Consent was gained from participants prior to taking part<sup>5</sup>. A topic guide and questions were developed in advance by the author, covering awareness of a problem, problem disclosure and methods of help seeking. The questions were not used verbatim but as a guide. The author's research skills guided the interview and questions asked. Interview preamble and questions can be found in Appendix H.

Demographic information was gathered from participants about themselves and the person with anorexia that included; age, gender and ethnicity. Participants were also asked if they had any experience of an eating disorder prior to the person they had supported, and at what age the onset of anorexia was for the person and duration.

### Qualitative Data Analysis

The data was analysed using Thematic Analysis,<sup>31</sup> which is a method for identifying, analysing and reporting themes within data. It is a theoretically flexible approach that can provide a rich and thorough account of the data.

The six phases of thematic analysis outlined by Braun and Clarke<sup>31</sup> were followed<sup>6</sup>. Initially transcripts were read and re-read to gain familiarity with the data. Initial codes were then generated across the entire data set. Codes were then amalgamated into themes and the themes were reviewed to ensure they fitted with the

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<sup>5</sup> See Appendix G for consent form

<sup>6</sup> The steps of analysis are further elaborated on in the extended paper methodology.

coded extracts and entire data set. The themes were then defined and named.<sup>31</sup> The analysis aimed to provide a rich thematic description of the entire data set. A hybrid inductive-deductive approach was used<sup>32</sup> and data was analysed at the latent level.

### Quality Assurance Measures

The study followed the recommendations of Henwood and Pidgeon<sup>33</sup> and Willig<sup>34</sup> for establishing the quality and trustworthiness of the findings. This included producing an “audit trail” with a thorough and detailed methodology that could be replicated. The analysis was supervised by the second and third author. Initial codes were checked and this helped to ensure that the themes identified fitted with the data.

## **RESULTS**

### Sample Characteristics

In total, 10 women took part in the study, aged between 25 and 68 years (mean age 50.4 years). Nine classed themselves as “White British” and one “White Australian”. The majority of participants reported that they did not have any prior experience of eating disorders before supporting the person with anorexia. Three stated that they had some awareness, gained from a University degree, indirectly through work, or experience with another family member.

Eight participants discussed supporting their daughter with anorexia, one discussed their partner and another discussed a friend. The participants provided the demographic information about the adult that they discussed in the interview. All participants had supported a woman with anorexia, who at the time of the study was aged between 18 and 30 years (mean age 23.3 years) and of “White

British" ethnicity. Age of onset of anorexia ranged between 14 and 24 years and duration of anorexia between 18 months and 6 years.

### Overview

Data analysis yielded four superordinate themes, which reflect the process of encouraging help seeking over time<sup>7</sup>: (1) first response; (2) confrontation and confession/denial; (3) stepping in and (4) "stepping back". There was a clear temporal pattern to this process.

### **First Response**

This theme relates to the participants' first reactions to initial changes in the behaviours of the person with anorexia. The first signs that participants noticed was that the person with anorexia started to change their eating habits or the amount of exercise that they did. Most participants were not immediately concerned by these observed changes, for several reasons. Four described that their initial reaction to the person with anorexia's weight loss was positive, as they perceived these new behaviours to be ways that the person was becoming healthier. Jane expressed later regret and shame about responding with praise to initial weight loss:

(Jane) *"I did notice that she had lost some weight, but in the stupid way that you do, I said, "oh god, you look fantastic in those new trousers."*

Similarly two other participants did not perceive initial changes in behaviour as a warning sign because of their own beliefs about anorexia and who might develop it:

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<sup>7</sup> Other themes are reported in the extended results.

(Linda) *I suppose I didn't look at her, in that way. I'd always thought she'd seemed quite robust, psychologically. And very sensible and you know, a very balanced girl."*

Other participants noticed initial changes in behaviour, but expected initial weight loss to be a short term:

(Jill) *"I know this sounds totally, completely against all the evidence of my eyes, but there was a part of me thinking, yes that's — it will all be OK. We'll just wait until we — we'll get her home at Christmas, we'll get her back to, you know, home cooked food and it will all be fine."*

Three participants tested out their initial suspicions that there was a problem, before they discussed their concerns with the person with anorexia. Participants tried modelling good eating habits, talking over their concerns with their GP, and challenging rules around eating, e.g.:

(Sue) *"I started to eat a lot more myself, because I was trying to set a good example for her...So I'd be eating larger meals than I wanted to, and I'd be forcing myself to eat, so I could show her that's what we should be doing."*

### **Confrontation and Confession/Denial**

Six participants described a specific moment where they became really concerned about the person. For five, this was when they became aware of how much weight the person with anorexia had lost. Other moments included finding hidden food or the person disclosing a behaviour that really concerned the participant. What was similar across these moments is that they sparked fear in the participant that there was a serious problem, which led them to confront the person with anorexia about their eating.

(Sue) *"I had to be clear, on the face, that there was a huge line that had been crossed, and that—, that was the thing, that made me sure that there was a problem, and I said "that is definitely an eating disorder thing, that's not just your lifestyle, that's not just you looking after your body, that's not you like enjoying exercise, that is self-harm and it is dangerous and it will hurt you, and you're doing that to your body on a regular basis. That is an eating disorder."*

When participants confronted the person with anorexia about their eating, the majority confessed to having a problem and only a few denied a problem. This might have been because the confrontation was unexpected. The following quote demonstrates how powerful confrontation could be in eliciting a 'confession':

(Helen) *"I was really shocked and I said, "darling, that's far, far too much to lose, look at you, you're too skinny now, what's been going on please?" and she said — she just broke down and told me straight away that she'd been appearing to eat normally in front of us."*

Some participants discussed some of the potential difficulties of reacting so quickly when they were anxious,

(Helen) *"She always said that I always came across as really rude and angry with her, and I think it wasn't that. It was that I was panicking and worried and —, but I can see how that would translate to them."*

In contrast to most participants whose confrontation actions were fuelled by fear, one participant actually stopped and reflected on the impact that confronting the person might have on their relationship with them.



(Jane) *"If I was to say to her, you've got an eating disorder, you need to go and get help, I don't think she would have done anything. I think I would have lost a friend."*

Three participants did not confront the person about their eating. The person self-disclosed their eating problem to the participant or to their GP. According to participants, neither method of confronting the person, or the person self-disclosing their eating problem, clearly had a more favourable outcome, as both resulted in the person with anorexia going to the GP.

All participants that tried, reported that they were successful in encouraging the person with anorexia to go to the GP as the first port of call. This initial GP appointment was a significant moment, as it was an opportunity to be referred for treatment. However, the majority of participants reported that it did not lead to a referral for treatment, because the person's weight was not deemed low enough, or the problem was undetected or minimised. This seemed to create another role for these participants, and they stepped in to continue to try and support the person to seek help.

### **Stepping In**

Stepping in describes a style of support frequently described by participants, generally occurring early on. Stepping in seemed to occur following confrontation and may reflect the participants fear about the person which led them to take control. For many stepping in occurred when the GP appointment had been unsuccessful in leading to a referral for treatment.

This theme contains examples of participants being proactive in trying to get the person with anorexia to seek help. Their approach early on was direct and persuasive. They used a range of methods in trying to support the person and it became apparent during the later stages of analysis that the patterns in this theme mapped onto an

existing theory of social support<sup>35</sup>. The following subthemes map onto the theory: informational, practical and emotional. Informational support might include giving someone advice, practical support is tangible support and emotional support is providing love and care<sup>35</sup>.

#### i) Informational Support

This was the main method of support that participants used and includes information that participants gathered for themselves and information gathered for the person with anorexia about treatment options. Most participants described being eager for information to help them to understand what to do to support the person to seek help:

(Jill) *"We did do absolutely everything, erm, anybody suggested. I mean we were, we were clamouring for, you know, in ourselves, we were clamouring for as much help as we could get, erm."*

Participants reported that they educated themselves by accessing a range of resources. They sought advice from professionals and others with shared experience. Eight participants reported that they looked on the internet for information, seven reported that they attended a carer group, conference or workshop, and nine reported that they read books:

(Helen) *"I felt completely out of my depth because this child was now a young adult and not wanting support. So I started going there for tips and to a couple of the workshops that they run."*

Linda described being eager for expert advice and contacted directly, one of the leading professionals who specialises in the research and treatment of eating disorders in the UK:

(Linda) *"I actually had some email correspondence, at one point where I was desperate, with Janet Treasure and she referred me on to a carers group which runs conferences."*

Some participants also gave the person with anorexia information about available help. Sue tried to make it easy for the person with anorexia to seek help and tried to pre-empt and remove any barriers to engagement:

(Sue) *"I made this menu almost of therapists and I put this map on, to show how long it would take her to get there and so how long it would take her to get there from work, how much it would cost, what their experience was, qualifications were and their style was. I made it so that all she had to do was turn up, and even just, on the phone shooting therapists down on their costs, so that she wouldn't worry about the money involved and all of these things."*

## ii) Practical support

Participants offered practical support to encourage help seeking such as booking treatment appointments, chasing up referrals or attending appointments with the person with anorexia:

(Sue) *"I went with her to the appointment and sat in the waiting room, she went in and I just waited for her outside."*

It appeared that fear about the person's health underpinned the practical support being offered by participants. Sally asked a friend whose daughter had also had anorexia about help available and immediately followed up the recommendation,

(Sally) *"Joan had put down her car window I said "help" and she was fantastic. But erm, she told me about a private clinic she had been involved with in London and I managed to get*

*Claire an appointment with the psychiatrist there, literally, the next day."*

### iii) Emotional support

Some participants reported providing the person with anorexia with emotional support throughout the process of trying to encourage them to seek help:

*(Diane) "After mealtimes I would rub her back and we would, you know, I would calmly talk about the fact that I couldn't see into this darkness that she was in...I just emphasised the fact that I was going nowhere."*

Emotional support changed over time. Initially some participants described feeling frustrated and hostile towards the person for not eating or seeking help, but over time became more compassionate towards them. This change appeared to reflect the participants understanding of anorexia over time. Initially perceiving anorexia to be a choice, to then perceiving it as separate to the person:

*(Linda) "It's the illness that's making her behave this way and not — that's not who the person is. The person's still somewhere in there."*

*(Sally) "Be very gentle and caring and maybe to [pause] erm, to remember that they don't want to be like this and I think the thing that it took me, I didn't realise at the beginning, was how starving Claire was, You know that bad tempered and stuff, she was starving and so to understand that I guess that they, they're not in control of what's happening to them and you can't just 'pull yourself together'."*

Kate worried if providing emotional support was unhelpful and hindered her daughter accessing professional help:

(Kate) *"I don't know, sometimes I think that perpetuates the illness, you know. If it was less comfy to come to, erm, maybe she would go and get professional help, you know."*

#### iv) Cognitive Support

This method of support did not map onto the existing theory of social support. Cognitive support was used to try and broaden the perspective of the person with anorexia, to try and help them to consider the impact of anorexia and potential alternatives. One participant encouraged the person to visit a hospital ward to see others suffering. Whilst others encouraged the person with anorexia to think about their aspirations for the future:

(Diane) *"But there were just, we also wrote lots and lots of lists. Lists about what you can do as an anorexic, what you can't do as an anorexic. What you would like to do in twelve months times, what you would like to do in five years time, could you do that? Honestly, I could paper the wall with lists. But we were just thinking about life beyond anorexia."*

Stepping in reflected early on direct approaches driven by the participants fear, and were aimed at encouraging the person with anorexia to seek help.

#### **"Stepping back"<sup>8</sup>**

The final key finding was that over time, the majority of participants reported that they stepped back in their approach. This meant that they sought to be calm and suggestive in their approach, rather than confrontational. Participants reported that this was either because direct and confrontational approaches were unhelpful, or they were advised to by others. Over time they realised that they could only modify their own behaviour. This stepping back was

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<sup>8</sup> This theme name is in quotations as it was the direct words from the participant.

reflected in their approach to encourage the person to access treatment:

(Sue) *"I sent her the links to blogs, we ended up having an agreement that if I had something I wanted to talk to her about or something I'd read that I would email her about it. Then she could chose when she read it, rather than me like forcing the information on her, cause sometimes she found that quite overwhelming."*

Sometimes, the exhaustion of more direct approaches led to stepping back:

(Sue) *"I was always pushing, pushing, and trying to stop her doing damaging things and that on the days or the weeks, where I just can't bear it anymore and I'm just so tired and I just give myself a bit of time, then she kind of has a bit of space to realise what I've been saying, not what I've been saying but basically (inaudible) and she listens."*

Some participants reported that they sought personal therapy as a result of trying to support the person with anorexia to seek help, and three reported that they were advised through this to step back. Two reported that they were advised at a carers group about stepping back. Some of these participants described how animal metaphors were used in the carer groups or in books for carers, to illustrate common behaviours and emotional response that individuals supporting someone with an eating disorder might find themselves drawn into. Participants reported that they were striving to be a "dolphin" <sup>36</sup> in being non-confrontational but supportive:

(Linda) *"I recognise myself in the beginning being a complete jelly fish and a bit of an ostrich and a bit of a rhino, you know confronting it, head on. And so my sort of aims for myself was*

*to sort of turn myself into a dolphin, not always successfully (laughs) and the Bernard."*

Many participants did not find "stepping back" easy:

*(Jill) "The whole idea of kind of being supportive and nudging them and being patient and so on. And I think I've tried — or we rather, have tried to move much more in that direction. I have to say we don't always manage it."*

Some participants only stepped back so far. Helen described how she still tried to maintain some control through the partner of the person with anorexia:

*(Helen) "Look, well if you're ever worried, please call the ambulance and please do this and you know."*

Not all participants commented on whether stepping back was an effective approach, but the majority reported that direct and confrontational methods of support were unhelpful. Four participants did report that stepping back was effective. Sally reported that stepping back seemed to empower her daughter:

*(Sally) "I guess we're learning, not to push her and we're [pause] so I guess that's the main thing, we're learning to let her set her own boundaries and make her own decisions and she is starting to want to look outwards a bit more, which is nice."*

Diane reported that stepping back had a beneficial impact, and by giving her daughter the control back, she came to her own decision to seek help.

*(Diane) "The person has to come to anything that they do themselves. And so I gave her the details, showed her where it was, said where it was, and probably about four weeks later*

*she then said, "I think I'm going to go to that thing". She had sort of worked through it in her own way."*

## **DISCUSSION**

Of the key findings reported in this paper, two support existing ideas in the literature and three are entirely novel.

The majority of participants in this study reported that initial observed changes in the person with anorexia's behaviour did not immediately cause them to be concerned. This finding supports previous qualitative studies that explored parents experiences of recognising the signs of anorexia in children and adolescents.<sup>21,37</sup> The findings from this study support a previous study, that found that early observed changes were normalised and initial weight loss was viewed as positive and was expected to be short term.<sup>21</sup> Information about the early signs of anorexia is available on the internet, but as the participants in this study reported, the signs can be hard to detect. This might be because apart from weight loss, some of the other first signs may be hidden and not initially apparent.

For the majority of participants in this study who confronted the person with anorexia about their eating, it resulted in a confession of a problem. A previous study found that confrontation by a significant other could lead the person with anorexia to seek treatment, if they were at the stage of wanting to change their behaviour<sup>18</sup>. It could not be concluded from the present study whether confrontation led to participants seeking treatment. What this study found was that following problem disclosure, all participants reported that they were successful in getting the person with anorexia to go to the GP, as the first port of call. This suggests there is an opportunity at this first GP appointment for a referral for treatment.



The findings reported in this study concerning initial contact with the GP are consistent with previous research.<sup>21,37</sup> The majority of participants in this study reported that the GP did not always detect the early signs of anorexia in the person and a poor response seemed to be a missed opportunity for some to be referred for treatment. Previous studies have found that when people went to their GP with initial concerns, the early signs of anorexia were not detected or minimised, which resulted in delays in seeking treatment.<sup>21, 37</sup>

It is widely accepted that early intervention is useful and getting help early for an eating disorder is associated with better prognosis and recovery outcomes<sup>10</sup>. Some reasons that have been suggested that might explain poor detection of eating disorders by the GP, include the GP having little experience of eating disorders, or not identifying them in groups not traditionally considered to be at risk.<sup>38</sup> This might be the case with adults, if GP's expect anorexia to be predominantly a condition in adolescence. Some participants reported that the GP did not refer the person with anorexia for treatment, because their body mass index was not low enough. This might reflect a problem with solely using clinical thresholds as a gateway to accessing services. Poor detection might also be because the person with the eating problem does not report a problem to the GP. Denial and secrecy are common behaviours in anorexia.<sup>17</sup> This study did not gain insight into what the person with anorexia said in their GP appointment, although one participant that attended the appointment reported that the person denied having a problem to the GP.

For some participants in this study, when the appointment at the GP did not lead to the person with anorexia being referred for treatment, it created a further role for them. Participants stepped in, and were active in investigating treatment options and encouraging the person to seek help. This has implications for the role of

significant others in help seeking, as it suggests their role does not stop at problem identification.

This study supports previous findings that individuals with an eating disorder will disclose their eating concerns to someone close to them, commonly friends and family.<sup>14-15,39</sup> This study makes an original contribution to existing research, through finding that some significant others of an adult with anorexia can initiate problem disclosure.

One of the study findings was that participants became knowledgeable in trying to encourage the person with anorexia to seek help. Participants drew on a range of resources to help them to understand what to do to support the person. To our knowledge, this is a novel finding. Some of these resources that participants accessed may have influenced their actions. Initial perusing of the resources available online for people supporting a person with an eating disorder match some of the responses of participants in this study, such as the advice to initially go to the GP and information about treatment options.

The study also found that many participants reported that more direct approaches in trying to encourage the person to seek treatment were unhelpful, and through experience or advice from others, they stepped back in their approach. As far as we are aware, this is the first study to identify this. Some carer groups are based on the "New Maudsley Method"<sup>36</sup> which teach carers motivational interviewing techniques<sup>40</sup> and communication skills<sup>40</sup> which might have influenced some participants to step back in their approach. Although, not all participants reported that they were informed to step back through attending carer groups or reading books for carers.

Initial direct approaches that participants used seemed match behaviours common in expressed emotion, which is considered to be

a maintenance factor in anorexia nervosa.<sup>41</sup> Therefore, advice to step back may be appropriate, and it should be emphasised to significant others to do this earlier on.

Implication of research for psychological theory

The ability to make generalisations from qualitative research is limited, but the findings reported by participants in this study can be readily understood using the stage model of grief by Kübler-Ross<sup>42</sup>. According to this model, people move through five stages of emotional adjustment in reaction to grief; denial, anger, bargaining, depression and acceptance. In this study, many significant others reported a sequential process in encouraging the person to seek help for their anorexia. The stage model of grief <sup>42</sup> can be applied to the experiences of the significant others, with some stages of the model more supported than others. See Table 4.

*Table 4.*

How the study themes map on to the stage model of grief<sup>42</sup>.

<b>Study Theme/Subtheme</b>	<b>Stage it maps onto in the grief model<sup>46</sup>.</b>
First response	Denial
First response	Anger
Self-Care	Depression
Stepping Back	Acceptance

The themes reported by many participants that could be considered to fit with the stage model of grief<sup>42</sup> will now be discussed. Many participants reported that their first reaction to observed changes in the adult’s behaviours around eating and exercise was denial that it could be anorexia, which maps onto the first stage of

the grief model<sup>42</sup>. Many participants reported feeling angry that the initial GP appointment that the adult went to, after confessing to having a problem with their eating, did not lead to a referral for treatment. This maps on to the “anger” stage of the model. Many participants reported stepping back in their approach. They were no longer confrontational and direct in their approach, but supportive alongside the person. This could be understood as participants reaching a stage of acceptance and maps on to the stage of acceptance<sup>42</sup>. There was no evidence of the stage of bargaining. Please see extended introduction and discussion for further information. The theme self-care is discussed in the extended discussion as it is reported in the extended results.

#### Implications for clinical practice

This study was an exploratory piece of research and makes several recommendations for clinical practice.

Firstly, there was a missed opportunity for some people to be referred for treatment at the initial GP appointment, so better early detection of anorexia in primary care is recommended. There may be clinical thresholds for services which prevent GPs being able to refer people at the mild to moderate stage, but the importance of early intervention for this group needs to be emphasised to professionals involved in the person’s care.

Participants drew on a range of resources to help them to understand what to do to support the person, looking online, in books, and seeking out information from carer groups and from others. Information about what to do could be concisely combined into one source and available online or at the GP surgery, so that participants are not delayed in accessing this information when they require it.

This study suggests that significant others may be important to target to help support someone to seek treatment, as they have an important role in problem disclosure and facilitating an initial appointment to the GP. Participants in this study also showed commitment to being involved in helping the person to seek help and there may be scope for the significant others to help deliver interventions, with permission from the person with anorexia.

Lastly, stepping back was the key finding of this study. Although it cannot be confirmed if this was helpful, more direct approaches were reported to be unhelpful. This study found that although some participants reported that stepping back was difficult to do, the rationale behind it was accepted and participants reported that they tried to endorse it. Therefore, it might be that significant others are encouraged to step back in their approach in supporting someone with anorexia earlier, but supported in doing this, as it is acknowledged that this transition may be difficult in practice. Motivational interviewing and being less directive might be implications for psychologists working with anorexia. Some limitations of using motivational interviewing with this population have been highlighted. Due to the physical risks of anorexia there is only so long that individuals can be left before forced to have treatment.<sup>31</sup> Blake, Turnball and Treasure<sup>31</sup> offer recommendations for working around these limitations.

#### Study limitations and recommendations for future research

In this section some limitations of the study discussed and then some recommendations for future research are outlined. Firstly, retrospective interviews used as the method raises the issue of reliability of the reports from participants, which could have been subject to hindsight bias. However, the primary researcher looked for consistency amongst participants' accounts and matched findings onto existing research.

A further limitation was that participants were mostly self-selecting and so respondents would have had an interest in the area, hence coming forward to take part. Furthermore, most of the participants in this study were recruited from the same carer group and two were recruited via snowball sampling from someone who had taken part. Although the carer group covered a large geographical area in England, it would have been useful to recruit from some other places to hear different voices.

This study found that first contact with the GP was highly important, so future research might further investigate how primary care reacts to help seeking. Future research projects could also test the adequacy of information sources available for carers by carers, and explore carer preference for information to help to tailor resources to match their needs. Many participants in this study accessed a wide range of resources to try and find out what to do and some were unhelpful and delayed them in accessing helpful information.

In summary, this is the first study to explore help seeking in adults with anorexia from the perspective of the significant other. The study findings support previous research and make original contributions around the role of significant others in problem disclosure, and in finding that significant others educate themselves about what to do to support the person to seek help. The message of stepping back was endorsed by participants', after more direct approaches were reported to be unhelpful.

### **Disclosure of Conflicts**

There is no conflict of interest to declare by the authors.

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## **Appendices**

## Appendix C: Ethical approval letter



11 11 2013


Dear Samantha Cox,

Thank you for making the changes that the committee requested. On behalf of the School of Psychology Research Ethics Committee (Soprec) I wish to inform you formally that at our meeting (October 2013) your proposal " Help seeking in adults with anorexia: What is the role of significant others? , was approved.

For future reference your project has been identified by the code 131111sc.

Good luck with what promises to be a very exciting project.

Yours sincerely,

A handwritten signature in blue ink, which appears to read "Patrick Bourke".

Patrick Bourke, PhD

Chair, School of Psychology Research ethics Committee  
University of Lincoln  
Brayford Campus  
Lincoln LN6 7TS  
United Kingdom  
telephone: +44 (0)1522 886140

## **Appendix D: Amendments to ethics – copy of emails**

**Monday, November 11, 2013 12:26 PM**

Hi Sam,

This has now been reviewed and ethical approval is given. There is one small point, could you please delete the underlined. I feel makes it currently is a little unclear as to the involvement of the NHS ethical approval stream with regards to this study.

Good luck with your research,

Patrick Bourke PhD  
Chair Soprec,  
University of Lincoln

### **Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the University of Lincoln Ethics Committee

**Monday, November 11, 2013 12:32 PM**

Hi Patrick,

Thank you for getting back to me. Glad to hear I have ethical approval. Yes will delete the part you highlighted.

Best wishes  
Sam

**Monday, January 20, 2014 10:46 PM**

Hi Patrick,

I have received ethical approval for my project but I was just reading over my consent form before I posted it out to my two participants and I wasn't happy with a couple of things with it, and wondered if I could make a couple of changes to it before I send it out? I have not sent any yet, but need to send two this week.

I have attached the old and new consent form for ethical approval.

This consent form will be emailed to participants to sign and return in a SAE if they do a telephone or Skype interview, or to sign in person if they do a face to face interview.

**Samantha Cox**

Trainee Clinical Psychologist  
Trent Doctorate in Clinical Psychology

**Tuesday, January 21, 2014 11:40 AM**

Hi Sam,

What do you want to change ?

Patrick  
Patrick Bourke PhD  
School of Psychology  
University of Lincoln  
Lincoln  
UK

**Tuesday, January 21, 2014 7:57 PM**

Hi Patrick,

Changing point 3 on the consent form from: I understand that all information given by me or about me will be kept anonymous and non-identifiable.

To :I understand that all information given by me or about me will be treated as confidential and that all identifiable information will be anonymised.

And changing the part where the participants signs the form from:

Name of Participant	Date	Signature
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Name of Person taking consent	Date	Signature
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**Changing it to:**

Please Print Full Name	Date	Signature
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Lastly, I have also just added the title of the project to the consent form and made the boxes of the option to opt in or out of receiving



the findings when the study is finished larger (although these last two changes are not ethical issues).

Best wishes

Sam

**Wednesday, January 22, 2014 8:26 AM**

Hi Sam,

These are excellent changes and if anything improve the ethical quality of the proposal. I am happy to approve them by Chair's Action.

Best wishes,

Patrick

Patrick Bourke PhD  
Chair Soprec  
School of Psychology  
University of Lincoln  
Lincoln  
UK

**Wednesday, January 22, 2014 3:55 PM**

Hi Patrick,

Thank you for your email confirming ethical approval for the amended consent form. I hope the following request will be the last amendment to my ethics form that I put forward to you; it is concerning recruitment and I have spoken to my research supervisor today.

I would like to add to the original recruitment strategy. Would an email outlining the addition to the recruitment strategy be suffice for you to consider ethical approval or do I need to submit a new EA2 ethics form?

Best wishes

Sam

**Thursday, January 23, 2014 2:16 PM**

Hi Sam,

Actually I'm pleased to see such a thoughtful approach to the project. An email should be fine and I will hopefully be able to deal with it by Chairs Action.

All the best,

Patrick

**Thursday, January 23, 2014 4:34 PM**

Hi Patrick,

Thank you.

In my current EA2 ethics form it reads as follows;

Recruitment

Participants will be recruited from support groups for eating disorders; (e.g. FirstSteps, Freed Beeches. I plan to go along to support groups to promote the study. Participant information sheets will be left and individuals interested in taking part will be asked to contact me (on a work mobile phone) using the details on the sheet. The study will also be advertised on the following websites; BEAT and [anorexiacarers.co.uk](http://anorexiacarers.co.uk).

I would like to ask to make the following amendments/additions to the above:

I would like permission to attend support groups in the UK for individuals with eating disorders and groups for carers of people with eating disorders. With permission from the service, I will attend these support groups to talk about my study and leave some copies of the study flyer/ brief information sheets with an allocated clinician to hand out to anyone that expresses interest in taking part and some copies of the full information sheet if people would like some further information. I would also like permission to advertise my flyer/brief information sheet on notice boards in these services (with permission from the service).

I would also like permission to circulate the flyer/brief information sheet for my study via the website "eating disorders and carers" (<http://eatingdisordersandcarers.co.uk/>) and other relevant websites dedicated to support carers of people with eating disorders in the UK that may be brought to the research team's attention during

recruitment and websites set up for those with eating disorders (e.g. BEAT) which carers may still access.

Anyone who is interested in participating in the study can contact myself (via the details on the flyer/brief information sheet) and will be sent the full participant information sheet, via email or post.

Once someone has received this information sheet, a minimum of 48 hours will be recommended between receiving the information sheet and deciding to take part. Participants will be asked to take part in a one off interview, lasting between 60 and 90 minutes with myself, the Chief Investigator. A signed consent form will be required prior to taking part. Face to Face interviews will be conducted, with permission at the service base where the participant was recruited, or a room at the University of Nottingham or the University of Lincoln. Skype and telephone interviews will also be offered. Participants will be interviewed in order that they volunteer to participate.

Best wishes

Sam

**Friday, January 24, 2014 9:24 AM**

Hi Sam,

I am happy to approve the changes described below. As far as the Soprec is concerned you have ethical approval.

Good luck with your work,

Patrick

Patrick Bourke PhD  
Chair Soprec  
School of Psychology  
University of Lincoln  
Lincoln  
UK

**Friday, April 04, 2014 4:26 PM**

Hi Patrick,

I require a very minor amendment that requires ethical approval. I would like to use a transcription service to transcribe audio recording with my participants. I have added a line of information on both the consent form and participant information sheet (and highlighted in yellow for you to review) to reflect this.

I have had contact with the transcription service who have confirmed they are happy to sign the University of Lincoln's confidentiality agreement prior to transcribing any interviews.

Best wishes,  
Sam

**Thursday, April 10, 2014 11:15 AM**

Dear Samantha,

I agree this minor modification by Chairs Action.

Best wishes,

Patrick Bourke PhD

Chair Soprec  
School of Psychology  
University of Lincoln  
Lincoln  
UK  
(0)1522 886180

## Appendix E: Participant recruitment flyer



# Do you know an adult with anorexia?

If you have been there to support a friend or loved one with anorexia, you could be of great help to a new study.

I am looking for friends, parents and partners who have supported an adult with anorexia to seek help for their eating problem.

I am interested in hearing about your experience.

My name is Samantha Cox. I am a Trainee Clinical Psychologist at the University of Lincoln. The study involves a one off interview, lasting between 60-90 minutes, which can be done in person, over the telephone or by Skype.

If you would like to take part or find out more information, then please contact me by telephone or email:

**Samantha Cox**

**Trainee Clinical Psychologist**

Email: [12354172@students.lincoln.ac.uk](mailto:12354172@students.lincoln.ac.uk)

Project Supervised by:

**Dr Mike Rennoldson: Academic Supervisor and Clinical Psychologist**

International House, Jubilee Campus, Wollaton Road, Nottingham, NG8 1BB, Telephone: 0115 846 6670.

Email: [michael.rennoldson@nottingham.ac.uk](mailto:michael.rennoldson@nottingham.ac.uk)

## **Appendix F: Participant Information Sheet**



### **Participant Full Information Sheet**

#### **Title of Study:**

**Help seeking in adults with anorexia:**

**What is the role of significant others?**

#### **Name of Researcher:**

The chief investigator is a Trainee Clinical Psychologist, Samantha Cox, based at the University of Lincoln and employed by Lincolnshire Partnership Trust.

The research is supported by a team of Clinical Psychologists:

Dr Mike Rennoldson (academic supervisor) from the University of Nottingham

Dr Anna Tickle, from the University of Nottingham (academic supervisor).

Thank you for taking the time to read this information sheet.

I would like to invite you to take part in a research study about how family and friends of an adult with anorexia try to facilitate them to seek help. Before you decide whether to take part, it is important you understand why the research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with others if you wish. If any of the information is unclear or you would like further information, please contact me. Please take your time to decide whether you wish to take part (we recommend a minimum of 48 hours).

## **What is the purpose of the study?**

Sometimes individuals will talk about their eating problems to those close to them, and many will open up to a family member or friend before a professional. This can sometimes leads to the individual seeking help for their eating problem, but sometimes does not. Those close to an individual with anorexia might try different ways to encourage them to seek treatment.

Through interview, this study aims to find out more about the role of family and friends in trying to support adults with anorexia to talk about their problem and to seek help.

Questions will be asked about the onset of the anorexia, when you first noticed there was a problem; how disclosure of the problem was approached, what you tried to do to try and support the person to seek help and the outcome.

Sharing your experience may help other families and friends struggling to help an adult in a similar situation. Furthermore, it may go towards providing information for some self-help materials being developed to support families and carers of individuals with anorexia.

## **Can I take part?**

You may take part if:

- You are a significant other of a male or female adult with anorexia.
- You are aged 18 years or older.
- You have tried to influence an adult (aged 18 years or older) to seek help for anorexia nervosa.
- You are able to communicate verbally in English for participation in a semi-structured interview.

I am aiming to recruit up to 15 participants.

## **Do I have to take part?**

No. It is up to you whether you decide to take part or not. Participation is entirely voluntary. If you do decide to take part you will be given a copy of this information sheet by the researcher and asked to sign a consent form.

You are free to withdraw from the study at any time without penalty. If you decide to withdraw, you have up to 72 hours following the interview to request that your data be destroyed. After 72 hours, it will not be possible to withdraw your data because it will have already been transcribed and used for the project.

### **What will happen if I take part?**

If you wish to take part in the study and are eligible to participate, a convenient time will be arranged with you to conduct the interview. The interview will last between 60-90 minutes.

The interview will take place either:

- Face to face in a private room either at the service base where you heard about this study, or, if more convenient for you, a room at the University of Lincoln or Nottingham.
- By telephone
- By Skype.

The conversation will be audio recorded so the researcher can listen to it and transcribe it for the purposes of the research. If a professional transcription service is used to transcribe your interview, they will be required to sign a confidentiality agreement prior, a copy of which will be retained at the University of Lincoln.

### **What are the possible advantages and disadvantages of taking part?**

The interview may give you a chance to reflect on your own experiences of trying to get an individual with anorexia to seek help, which you might find helpful.

It is possible that disclosing your personal experiences may result in some distress. The researcher interviewing you will be sensitive to this and if necessary may stop the interview. If you become



distressed you may stop the interview at any time without having to provide a reason. If you have any concerns during or following the interview you will have the opportunity to discuss these. You will be given a list of support services and their contact numbers (please see end of this information sheet). You are free to withdraw from the study at any point, without having to provide a reason why.

### **What if there is a problem?**

If you have a concern about any aspect of this study, in the first instance please address this to the researcher (Samantha Cox), or research supervisor (Dr Mike Rennoldson), for both, the contact details can be found at the end of this information sheet. For an official complaint, please contact Dr Patrick Bourke at the University of Lincoln:

Contact details for Dr Patrick Bourke:

Address: University of Lincoln

Brayford Pool

Lincoln

Lincolnshire

LN6 7TS

United Kingdom

Email: [pbourke@lincoln.ac.uk](mailto:pbourke@lincoln.ac.uk)

### **Will my taking part in the study be kept confidential?**

Yes, personal information about you (your name, and contact details, including address, email and telephone number) will be kept confidential and will not be shown to, or shared with anyone outside of the research team. This data will be stored in a locked filing cabinet at the University of Lincoln.

Transcripts will be anonymised so that they contain no personally identifiable information when they are analysed and if any quotes are used in a publication. Your transcript and audio recording will be stored separately to the personal identifiable data in a secure locked filing cabinet at the University of Lincoln.

If you wish to be contacted about the findings from the study, your contact details will be retained until February 2015 after which they will be erased.

### **Limits to confidentiality**

Should you disclose anything that raises concerns about possible harm coming to you or others, then this information may need to be shared with the relevant individuals to keep you or others safe, but it would be discussed with you first.

### **What will happen to the results of the research study**

It is intended that the findings of the study will be published in a relevant peer-reviewed journal. All participants will be given the option to receive a summary sheet of the findings. Findings will also be fed back to services and websites involved and presented at relevant conferences.

### **Who is organising and funding the research?**

This research is being funded by the University of Lincoln.

### **Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the University of Lincoln Ethics Committee.

### **Further information and contact details:**

If you would like to take part in the study then please contact:

**Samantha Cox:**

**E-mail:** [12354172@students.lincoln.ac.uk](mailto:12354172@students.lincoln.ac.uk)

*Please let me know:*

1. Your preferred method of contact - email or telephone number (including the day/s and time/s that it is best to contact you).
2. Your preferred method of interview (face to face, telephone or Skype)

**Project Supervised by: Dr Mike Rennoldson**

International House, Jubilee Campus, **Wollaton Road**, Nottingham,  
NG8 1BB, Telephone: 0115 846 6670

Email: [michael.rennoldson@nottingham.ac.uk](mailto:michael.rennoldson@nottingham.ac.uk)

**Support services and Helplines:**

BEAT (Eating Disorders Support Service) Helpline: 08456 341414:

Email: [help@b-eat.co.uk](mailto:help@b-eat.co.uk)

First Steps Derby (Eating Disorders Support Service) Helpline: 01332

367571: Email: [info@firststepsderby.co.uk](mailto:info@firststepsderby.co.uk)

Samaritans (24 hours a day): 08457 909090: [www.samaritans.org](http://www.samaritans.org)

**Thank you for taking time to read this.**

## Appendix G: Participant Consent Form

Participant ID number.....

### Help seeking in adults with anorexia: What is the role of significant others?

Name of researcher: Samantha Cox

**Please initial box**

1. I confirm that I have read and understand the participant information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the study. If I withdraw up to 72 hours after the interview I can request that my data is withdrawn. After this time, I understand that it will not be possible to withdraw data from the study. ☐
3. I understand that all information given by me or about me will be treated as confidential and that all identifiable information will be anonymised. ☐
4. I give permission for my interview to be audio recorded and for anonymous direct quotes from the interview to be used in the study reports under a pseudonym. ☐
5. I give permission for my interview to be transcribed by a professional service who will adhere to the Data Protection Act (1998) confidentiality agreement. ☐
6. I agree to take part in the above study ☐

---

**Please Print Full Name**

---

**Date**

---

**Signature**

2 copies: 1 for participant, 1 for the project notes

### Optional (please tick "yes" or "no")

I would like to receive a summary of the findings of the study following its completion in October 2014. If so, the investigator will need to retain your contact details until February 2015 when this summary is sent out, after which they will be erased.

Yes ☐

No ☐

## Appendix H: Interview schedule

Could you tell me about your relationship with (name)? (Prompts; how long known them for, with AN, lived with them?)	
What did you know about anorexia before (name)?	
Has (name) sought support? (If yes, do you see this as a result of your actions?)	
What were the first signs that made you think (name) might need to seek support?	
What did you do? (prompt; did you seek advice from elsewhere? internet, other people?)	
How long were you concerned before you voiced your worries?	
How did you begin to share your worries with (name)?	
What happened? (Barriers/facilitators, did (name) agree they needed to seek support?)	
Tell me about your plans and intentions to get (name) to see support?	
How did you know, or find out, what help was available?	
Tell me about what you tried to do to support (name)?	
How did (name) respond?	
Did your approach in supporting (name) change at any time? (if yes, how?)	
Did your knowledge about anorexia change throughout you supporting (name)? (if yes, did it impact on your approach to support (name) to seek support?)	
Were there any times that you felt (name) almost sought help but didn't?	
What went well in your attempt to support (name) to seek support? (what would have done differently, if anything?)	

How has (name) reacted to the support you have given her/him?	
Has this experience changed your relationship with (name)? (If yes, how?)	
What would be your main piece of advice to someone who was trying to support someone to seek support?	
With regards to people with anorexia seeking support, what do you perceive their fears to be?	

Is there anything that I haven't asked today that you would like to say?

Participant No.....

### **Participant demographics**

Gender.....

Age.....

Ethnicity.....

Have you had any experience of an eating disorder before?.....

### **About the adult with anorexia:**

Gender.....

Age.....

Ethnicity.....

Age on onset of anorexia: .....

How long they have/had the condition for?.....

## **Extended Paper**

## EXTENDED PAPER

The extended paper is intended to be read in conjunction with the journal paper. It offers additional detail to supplement each section of the journal paper and concludes with a critical reflection of the research process.

### Introduction

#### Anorexia Nervosa

The symptoms of anorexia nervosa according to the DSM-V (American Psychiatric Association (APA), 2013) can be seen in Table 5. Two subtypes have been described: restrictive and binge eating / purging type, the latter of which engage in self-induced vomiting or misuse of laxatives (DSM-V, APA, 2013).

Table 5

*DSM-V (American Psychiatric Association, 2013) diagnostic criteria for Anorexia Nervosa*

---

- A) Persistent restriction of energy intake leading to significantly low body weight (in context of what is minimally expected for age, sex, developmental trajectory, and physical health).
- B) Either an intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain (even though significantly low weight).



Table 5

*DSM-V (American Psychiatric Association, 2013) diagnostic criteria for Anorexia Nervosa*

---

C) In the way one's body weight or shape is experienced, undue influence of body shape and weight on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

D) *Subtypes:*

*Restricting Type:* during the current episode of Anorexia Nervosa, the person has not regularly engaged in binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

*Binge-Eating / Purging Type:* during the current episode of Anorexia Nervosa, the person has regularly engaged in binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)

---

The DSM V (2013) has revised some of the criteria, removing that for a full diagnosis the person had to have full amenorrhea for three consecutive months (DSM-IV-TR, 2000). This criteria had received criticism for not being applicable to men or adolescent females (Anderson, Bowers & Watson, 2001). Furthermore, the subtypes of this diagnosis have received criticism for not providing criteria for what constitutes regular binge and purging behavior (Eddy et al. 2002). Regarding the two subtypes of anorexia, one study of 123 women in an eight year follow up, found that 62% of women crossed over from the restricting subtype to the binge eating/purging subtype, and only 12% of the women reported never engaging in any binge eating or purging behavior. This led to a conclusion that the

subtypes were not mutually exclusive but the restrictive type might just be a stage in the course of anorexia (Eddy et al. 2002).

#### Prevalence rates and co-morbidity of Anorexia Nervosa

The prevalence rate of anorexia varies amongst studies. One study reported that the lifetime prevalence of DSM-IV-TR anorexia was 0.9% amongst women and lower in men at 0.3% (Hudson, Hiripi, Pope Jr & Kessler, 2007). Another study reported lifetime prevalence rates of anorexia as estimated to be between 0.9-2.2% in females (Wade, Keski-Rahkonen & Hudson, 2011). In a community sample, prevalence rates for "full-syndrome" anorexia were 0.66% in women compared to 0.16% in men (Woodside, Garfinkel, Lin, Goering, Kaplan & Goldbloom, 2001). It has been stated that based on prevalence rates that eating disorder are uncommon (Hudson, et al. 2007). However given that some people with anorexia can be secretive about the condition (Vandereycken, 2006) it is perhaps more prevalent than what has been reported. Anorexia is commonly comorbid with depression and anxiety disorders, particularly social phobia and obsessive-compulsive behaviours (Pike, 1998).

#### Course of anorexia nervosa

Anorexia most commonly affects females aged between 15 to 19 years old (Hoek & van Hoeken, 2003) and begins with the onset of dietary restriction in the majority of cases. The restriction becomes extreme and leads to weight loss and the person may become significantly underweight (Fairburn, 2008). For some, the disorder is short lived, but it can become more severe in 10% - 20% of individuals (Bulik, Sullivan, Fear & Pickering, 1998).

Long term studies state that a proportion of individuals with anorexia will recover, but many will continue to have disordered patterns of eating, with some moving to more bulimic patterns or eating disorder not otherwise specified (EDNOS) (Pike, 1998). It is

acknowledged in the literature that there is not a clearly defined definition of recovery in anorexia (Higbed & Fox, 2010) and across studies, classifications of recovery and reported recovery rates are inconsistent (Hardin, 2003). For the most part, recovery has been objectively defined in terms of behavioural outcomes such as absence of symptoms, weight restoration, and improved scores on psychometric measures (Weaver, Wuest, & Ciliska, 2005). Although it is widely recognized that weight gain can occur, clients can still experience other difficulties, such as disturbed attitudes towards body size (Fenning, Fenning & Roe, 2002).

#### Treatment for anorexia nervosa

Attempts to demonstrate the effectiveness of cognitive behaviour therapy (CBT) in anorexia has yielded inconclusive results (Fairburn, 2005) and there is weak evidence to propose that psychological therapies may be appropriate to adults with anorexia (Fairburn & Harrison, 2003). Regarding the effectiveness of treatments in adults, a study was conducted on 84 adults with late onset of anorexia (mean age 26 years) long-duration of anorexia (mean 6.3 years) and a history of unsuccessful treatments. Individuals were randomly allocated to four treatments; family therapy, focal psychodynamic psychotherapy, CAT or a "routine" group, which was used as the control group. The control group had a 30 minute session with a trainee psychiatrist, where physical health was monitored, and information provided about the importance of regular meals. The treatment was one year, and 54 adults completed it. All three therapy options were found to be more effective than the control group, with family therapy and focal psychodynamic psychotherapy found to be significantly superior to the others. All of the adults' symptoms improved, although more than two thirds remained significantly underweight (Dare, Russell, Treasure & Dodge, 2001).

Anorexia is difficult to treat and drop-out rates from treatment are high, which poses a serious obstacle to treatment (Wallier, Vibert, Berthoz, Haus, Hubert & Godart, 2009). Rates of drop out for treatment of anorexia were reported to range from 20.2% (Surgenor, Maguire & Beumont, 2004) to 49.6% (Vandereycken & Pierloot, 1983) in a specialised inpatient services for eating disorders. Previous research in an inpatient setting found that patients with binge/purge anorexia subtype were more likely to drop out of inpatient treatment than the restrictive subtype, which led them to suggest that impulsivity might be a factor in the person's decision to drop out of treatment prematurely (Wallier et al., 2009).

Once more, post treatment, a large proportion of individuals with anorexia relapse. Recovery rates from anorexia have been estimated to be between 25-70%, with higher rates of weight restoration and lower rates of drop-out reported in studies on adolescents (Guarda, 2008). The reason for enhanced outcomes with adolescents has been suggested to be due to the involvement of parents in family therapy, whereas adults need to rely more on self-motivation for long-term success (Guarda, 2008). The higher recovery rates reported in adolescents compared to adults may be explained by the fact that adolescents' studied have usually only had anorexia a short time (about a year on average) compared to adults (five years or longer) and adults have often had prior attempts at treatment. It has also been suggested that adolescents might be more treatment responsive than adults with anorexia, because many of the maintaining factors that prevent change are not present in younger people (Fairburn, 2005). However what these maintaining mechanisms are and how they obstruct change is not clear.

Although the treatment literature has not identified an effective treatment for anorexia, it is important to continue to try and discover effective interventions, because early intervention is linked to better

recovery outcomes (Treasure & Russell 2011) and there are ethical considerations regarding risk of not intervening (Goldner, 1989). Although the role of treatment in recovery of anorexia is still unclear, most individuals do show improvements whilst in treatment. Once more, many studies have significant methodological flaws that limit the conclusions that can be drawn about treatment effectiveness (Agras, Brandt, Bulik, Sewell, Fairburn & Halmi, 2004).

### Problem Disclosure

As discussed above, longer delays in seeking help are related to poorer outcomes (Reas, Williamson, Martin & Zucker, 2000). Many factors might impede help seeking and these will be explored below under "help seeking". However, in order to access help, the person needs to acknowledge that they have an eating problem and disclose this (Gilbert et al. 2012) and unfortunately many individuals with eating disorders are unwilling to take this first step (Becker, Grinspoon, Kilbanski & Herzog, 1999).

Literature on disclosure of eating conditions is fairly limited. In a study of 71 females (mean age 28.9 years, age range 15-62 years) exploring first disclosure of eating disorder symptoms and help seeking (Gilbert et al. 2012), some lay people and professionals that initiated disclosure, prompted the person to seek help. The study found that first disclosure of eating disorder symptoms tended to be to mothers and friends than any other type of confident which confirms the findings of Hepworth and Paxton (2007). A significant association was also found between being older at first disclosure and faster access to specialist eating disorder services (Gilbert et al., 2012). Although the study suggested that older individuals were more likely to choose a proactive confident, such as a healthcare professional, whereas younger people (mean age 17.7 years) were more likely to disclose to their mother.

Mothers were found to be the most proactive confidants and most likely to initiate disclosure. Whereas few professionals were involved in initiating disclosures, the disclosure was more likely to be volunteered (Gilbert et al. 2012). This is likely to be because mothers see their children and notice changes, whereas professionals have no reason to see them unless the person goes to them with a problem. Disclosures to GP's experienced the least delay in seeking help compared to disclosure to a friend, which was not found to be conducive to help seeking (Gilbert et al. 2012). This is likely to be because professionals are familiar with the treatment pathway and able to refer individuals to services, whereas a friend may be less sure about how to facilitate help seeking following problem disclosure. This finding suggests that friends may need support with how to facilitate help seeking following problem disclosure.

A further study focused on anorexia and explored adolescents' parents' experience of recognition of a problem and the process of deciding to seek help (Thomson et al. 2012). It is uncommon that adolescents present themselves as having a problem, which puts responsibility on the parent to recognise the signs and to facilitate help seeking (Thomson et al. 2012). The qualitative study used interpretative phenomenological analysis (IPA) so was able to explore in depth the personal experiences of parents, and gain rich, detailed information about the process. Early signs of anorexia were attributed to ordinary development in adolescence and weight loss was expected to be only temporary. Parents' observed what happened with their child and used the internet to help them to recognise the problem. Parents' believed that their child's symptoms had to be severe to justify treatment from services. They sought professional help following unsuccessful attempts to change eating habits themselves (Thomson et al. 2012).

In a larger study of 216 adults, Becker, Thomas, Franko and Herzog (2005) conducted telephone interviews to investigate disclosure of eating concerns to professionals, family and peers. Whether the information was "initiated" by another or "volunteered" by the person themselves, 47.7% of individuals reported that they disclosed their concerns to someone. The most frequent type of relationship reported was sharing their concerns with a friend (86.6%), and this was found to have a beneficial impact on seeking help, followed by partner (56.5%) or parent (53.8%) respectively. Disclosure to a parent was not associated with increased treatment seeking. Slightly fewer individual's reported that they shared information with professionals (46.3%). The study found that if the individual did not initiate disclosure, they were willing to disclose their condition to someone, if asked. This finding might be important for someone trying to support an individual who they suspect to have an eating disorder. The sample in this study was all adults, but participants did not specifically have anorexia, as it was reported that they had "eating or weight concerns".

Less information about the disclosure experience can be drawn on from a quantitative study about eating conditions and help seeking. This study explored who women in college would look to for guidance and support, if they were worried about an eating disorder. Participants reported that they would talk to a friend first, followed by a partner and parent (Prouty, Protinsky & Canady, 2002). This response might be reflective of the samples, who were a group of adolescents at University that are probably more likely to be building close friendships and liaising with friends.

### Help Seeking

The ego-syntonic nature of anorexia can delay help seeking (Kyriacou, Treasure, & Schmidt, 2008) and often individuals will deny having the condition (Honey, et al. 2008). Many studies exploring

help seeking in eating disorders have concluded that the majority of people do not seek help (Evans et al., 2011). In a community sample of women diagnosed with an eating disorder, Mond, Hay, Rogers and Owen (2007) found that only 40% had sought professional help. Furthermore, Cachelin and Striegel-Moore (2006) reported that just 26.7% of Mexican American and European American women living in the community had sought help for an eating condition. Factors found to impede help seeking include: the belief one should manage the condition alone (Becker, Franko, Nussbaum & Herzog, 2004), feelings of shame, a fear of being labelled (Cachelin & Striegel-Moore, 2006), a belief the problem was not serious enough (Meyer, 2001) and low motivation for change (Hepworth & Paxton, 1997). Whilst these studies demonstrate that there are many reasons that people do not seek help, some of these reasons may be common barriers to accessing treatment for many mental health problems. In addition, these studies included participants with a range of eating disorders, and so reasons were not specific to anorexia.

Exploring help seeking from the perspective of others is an under researched area. A qualitative study interviewed both the parents and their daughters who had recovered from anorexia about the recovery process (Sharkey-Orgero, 1999). The study, although not specifically on help seeking, found that parents planned to confront their child about their eating. When they did confront them they offered to support them to recover. This confrontation was a significant moment because it led some daughters to ask for help and other daughters to recognise that they had to take responsibility for change themselves. The findings from this study suggest that a confrontation from a significant other can serve to highlight what the person with anorexia already knows internally and can be a prompt to seeking help. Other studies from the perspective of others, have to the primary author's knowledge only been explored with parents of



adolescents with anorexia, as discussed above (e.g. Thomson, et al. 2012).

### The stage model of grief (Kübler-Ross, 1969)

One popular approach to psychological adaptation to change is Kübler-Ross's (1969) stage model of grief. Developed from her observations with individuals who were dying, Kübler-Ross constructed a model of grief that suggests that people might experience five stages of emotional adjustment; denial, anger, bargaining, depression and acceptance. According to this model, normal adjustment to grief means that initial denial gradually fades and is replaced by acceptance (Telford, Kralik & Koch, 2005). The five stages of the model are described below:

#### Stage 1: Denial

Kübler-Ross (1969) found from her interviews that most patient's first response to finding out that they had an incurable illness was a provisional state of disbelief and denial.

#### Stage 2: Anger

The second stage of the model is anger. The first stage of denial cannot be sustained inevitably and it is eventually replaced by feelings of anger, envy and resentment. Anger is displaced in all directions and might be projected onto the environment at times; for example to the doctors and nurses caring for the patient or loved ones (Kübler-Ross, 1969)

#### Stage 3: Bargaining

At this third stage, though if only for brief periods of time, the individual may try and make some sort of bargain, in an effort to delay the inevitable happening. Most people make these bargains with God and keep them confidential (Kübler-Ross, 1969).

#### Stage 4: Depression

After moving through the first stages, feelings of denial and anger will be replaced with a sense of great loss, about losing everything and everybody that they love. If a person can express their sadness at this stage, they will find the final stage of acceptance much easier (Kübler-Ross, 1969).

#### Stage 5: Acceptance

If the person has had enough time and been given some support in working through the previous stages, they will reach this final stage, where they are able to start to accept what is happening. Patients who struggle and fight to the end, are likely to find it more difficult to reach this final stage of acceptance (Kübler-Ross, 1969).

The model was developed by Kübler-Ross's (1969) observations from her interviews with over 200 hospitalised men and women considered to have life threatening or terminal conditions. The model was revolutionary at the time of its development. Initially, it brought the difficulties of dying people to the awareness of the public and health care professionals and for many, it was the first chance to learn something of the world as experienced by dying people (Kastenbaum, 2000).

It remains the most familiar stage model of dying today. However, the model is not without criticism. One of the main criticisms, is that there is no evidence that the five stage occur in sequence. This has not been demonstrated by Kübler-Ross or by independent research (Kastenbaum, 2000). However, stage models are particularly difficult to test or disconfirm empirically, since some theorists including Kübler-Ross (1969), have stated that some people may experience more than one stage simultaneously, or may move back and forth among the stages (Wortman, Silver & Kessler, 1993). Therefore some might add caution to using the term "stage model" as

it implies that people move through each stage sequentially, which may not be the case. Once more, stage models cannot account for the diversity in outcomes that occur in response to loss. Trying to map an individual's reactions onto stages may mean individual differences are overlooked (Wortman, Silver & Kessler, 1993).

#### Transtheoretical Model of Change (TTM)<sup>9</sup> (Prochaska & DiClemente, 1983)

The TTM, sometimes referred to as the "stages of change model" (Prochaska & DiClemente, 1983) is a model for understanding behaviour change. It was originally developed by Prochaska & DiClemente (1983) to understand smoking cessation but has also been applied successfully to many health-change behaviours including obesity, exercise and health screening (Chen, Dengy & Pan, 2012). Despite widespread use, the model has been criticised for oversimplifying human behaviour (Bandura, 1998).

In their original research five stages of change were identified. Individuals were perceived as progressing linearly through each stage (See Figure 2). Below is a brief description of each stage from Prochaska, DiClemente & Norcross (1992):

*Pre-Contemplation* - At this initial stage the person has no intent to change their behaviour for the predictable future.

*Contemplation* – People at this stage are aware that there is a problem and are thinking about changing it, but have not yet made a commitment to action. People can stay at this stage for a long time.

*Preparation* – At this stage people are intending to take action.

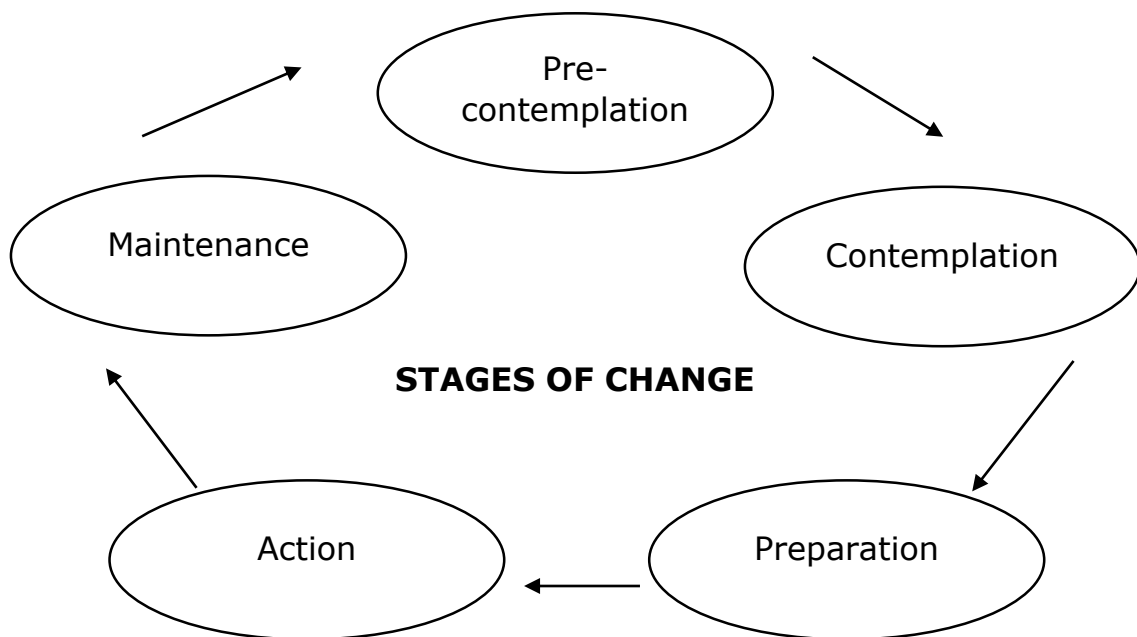
*Action* – The individual modifies their behaviour, environment or experiences to overcome the problem. This stage requires time commitment and energy.

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<sup>9</sup> This model is sometimes referred to as "Stages of Change Model" and the terms are used interchangeably in the literature.

*Maintenance* – People are consolidating their gains achieved in the action stage and at this stage the individual works at preventing relapse. Stabilising behaviour change and avoiding relapse are key points for this stage.

**Figure 2. Diagram of the original Transtheoretical Model of Change, (Prochaska & DiClemente, 1983).**



The original TTM model was later refined to the “spiral pattern of change” (Prochaska, DiClemente & Norcross, 1992) (See Prochaska, DiClemente & Norcross, 1992) as it was noted that many people who modified their behaviour do not successfully maintain the new behaviour on the first attempt. The original model was progressed from a linear model to a spiral that illustrates that people move from pre-contemplation to contemplation and to action and maintenance, but recognising and incorporating that at some point most people will relapse and regress to an earlier stage.

The TTM allows us to understand *when* shift in intention and behaviour occurs. The processes of change are a second dimension of the model that enables us to understand *how* these shifts occur. There are ten processes of change, divided into experiential and behavioural categories, and they are stage-matched. Consciousness raising, dramatic relief, environmental revaluation occur during Pre-contemplation, self-revaluation occurs during Contemplation, self-liberation occurs between Preparation and Action, while contingency management, helping relationship, counterconditioning, and stimulus control occur during the Action and Maintenance stages (Prochaska, DiClemente & Norcross, 1992).

The process named “helping relationships” is about the role of social support in helping to facilitate change and includes being open and trusting with others about your problems. Helping relationships might refer to self-help groups, social support and the therapeutic alliance (Prochaska, DiClemente & Norcross, 1992). Helping relationships are emphasised as being important at the action/maintenance stage of the change and help people to make and maintain change (Prochaska, DiClemente & Norcross, 1992). Although there has been a lot of literature about the main stages of change, the processes of change have received less attention in research.

The TTM has been used to understand and engage people with eating disorders in treatment and successful in its application for use in anorexia (Ward, Troop, Todd & Treasure, 1996). Blake et al. (1997) used the model with outpatients with a diagnosis of anorexia and bulimia and assessed stage of change before their first assessment. The study found that the majority of individuals diagnosed with anorexia were at the “pre-contemplation” or “contemplation” stages which might suggest that people with

anorexia may be pushed to change when not ready, due to their low weight.

### Social Support Theory

Since the 1970's the concept of social support and its impact on health and wellbeing has been a source of interest to academics and those working in areas in health (Turner, Hays & Coates, 1993). Social support is a multidimensional construct conceptualised and measured in a variety of ways (Rodriguez & Cohen, 1998). There is a large literature base on social support which is beyond the scope of this paper to discuss, but for a recent review of received and perceived social support please see Nurullah (2012). Research indicates that social support often mediates the negative impact of stressors (Cohen & Wells, 1985), suggesting its significance for prevention and intervention strategies (Turner et al., 1993).

Cohen and Wills (1985) describe different types of social support; emotional, informational, companionship and instrumental. Emotional support has been described as support that enhances someone's self-esteem by making them aware that they are valued for their own worth and unconditionally accepted. Informational support has been described as providing advice in understanding and coping with problems. Companionship may reduce stress through providing the person with contact with others. Lastly, instrumental support, is practical support, and might include providing financial aid or material resources. Schulz & Schwarzer (2004) also discuss different strands of support; emotional (e.g. showing love and care), informational (e.g. guidance and advice), and instrumental support (which refers to practical support, e.g. providing resources).

When an individual perceives an event as stressful it often leads them to feel hopeless and can contribute to feelings of low self-esteem. Positive social support has been found to be a beneficial

coping strategy for people experiencing emotional and physical distress (Stice, Ragan & Randall, 2004). It has been stated that emotional and informational support are the two types of support that can be applied to variety of events (Cohen & Wills, 1985), whereas the effectiveness of practical support and social companionship will depend on how well they match the need produced by the stressful event. For example e.g. practical support may not be suitable to offer someone who has recently been bereaved (Cohen & Wills, 1985). This is the idea behind the matching hypothesis (Cohen & Wills, 1985) which states that for social support to have a protective effect against the stress, the support resources that are perceived to be available must match the support needs produced by the stressful event (Cohen & Wills, 1985).

The above discusses social support more generally but specifically with regards to anorexia, people with anorexia have been described previously as being “enmeshed” with their families (Minuchin, Rosman & Baker, 1978). Given the age of this paper this is unlikely to be the view that you would hear today. This perception of individuals with anorexia has been said to affect the person’s development of autonomy (Stern, Whitaker, Hapeman, Anderson & Batgan, 1981). If this were true, then this might mean that adults with anorexia would only have a small network of social support around them which predominantly would be their family (Tiller et al. 1997). Tiller et al. (1997) tested this hypothesis in their study exploring social support in individuals with anorexia and bulimia nervosa, and found that people with anorexia (mean age 25.3 years) chose fewer people as sources of support compared to the comparison group. In line with their hypothesis, people with anorexia identified less people as support outside of their family, with few individuals nominating partners as sources of social support.

In anorexia, social support has been found to be a key element in recovery (Federici & Kaplan, 2008). Supportive and non-judgemental relationships were found to be a significant factor that helped to maintain changes achieved following treatment (Federici & Kaplan, 2008). Further support for the role of others in supporting a person with anorexia in their recovery journey comes from a systematic review of 18 studies on first person accounts of recovery from anorexia. Unconditional support by a close other was found to be a key factor in the process of recovery (Cox & Rennoldson, 2013).

So far the studies on eating disorders and social support have illustrated how supportive significant others can be to an individual with an eating disorder. Whilst this is true, another study explored helpful and unhelpful support from others. A qualitative study explored individuals' perspectives who had recovered from an eating disorder about how and what support influenced their recovery (Linville, Brown, Sturm & McDougal, 2012). Twenty two adult women were interviewed, 12 had recovered from anorexia, five from bulimia and five from EDNOS (eating disorder not otherwise specified) and they had been recovered for between one and 35 years. Participants reported that connections with others contributed to their recovery journey, as it made them feel more hopeful about recovery and talking to others helped them to normalise their experience. Relationships were given as a reason that made the person want to recover. A non-judgemental approach, positive statements, patience and emotional support were perceived as helpful support from others. Families that minimised the seriousness of the condition or believed that the eating disorder could be solved simply by the person increasing the amount of food that they ate were perceived as unsupportive (Linville, Brown, Sturm & McDougal, 2012). This study provided an insight into what might be helpful and unhelpful support to someone with an eating disorder, particularly relevant to this study



as a high proportion of the study sample had a diagnosis of anorexia. However, similar to this study, a limitation of the research was perspective bias (Linville, Brown, Sturm & McDougal, 2012), with only the person with the eating disorder reporting their account of the support offered by others. Gaining the perspective of those who had tried to offer support might have helped to 'triangulate' the study findings.

### Study Aims

The literature on problem disclosure illustrates that individuals will disclose their eating problem to someone close to them. Existing studies on help seeking in eating disorders highlight the barriers that people report to accessing treatment. However, for problem disclosure and help seeking, the studies have not specifically focused on anorexia, adults with anorexia or the perspective of the significant other. This study aims to address this gap and explore the role of significant others in problem disclosure and how they attempt to facilitate help seeking in adults with anorexia.

## **Methodology**

### **Ethical Considerations**

#### Ethical approval

Ethical approval was gained from the University of Lincoln on 11<sup>th</sup> November 2013. The wording and presentation of the consent form was amended and received approval on the 22<sup>nd</sup> January 2014. Further amendments included approval to circulate the study advertisement on a website and to use a transcription service and approval was gained on the 24<sup>th</sup> January 2014 and 10<sup>th</sup> April 2014 respectively.

#### Participant Information Sheet

An information sheet about the study was emailed to all individuals who came forward to take part in the study. A minimum of 48 hours was recommended between participants receiving the information sheet and giving consent to take part in the interview.

#### Participant Consent

All participants consented to their participation in the study prior to their interview. Hard copies of the consent form are kept in the study records held in secure storage at the University of Lincoln. Participants were also given a copy of their consent form for their own records.

#### Participant Withdrawal

Participation in the study was voluntary and participants were made aware that they had the right to withdraw without penalty. Participants were informed on the information sheet and consent form that if they did decide to withdraw, they could request that their data be destroyed for up to 72 hours following interview. The primary researcher's contact details were provided on the information sheet.

Through the information sheet and consent form, participants were made aware that after 72 hours it would not be possible for them to withdraw their data because it would have been anonymised and transcribed.

### Debriefing

The primary researcher's clinical skills were used to monitor participants during the interview. The author was aware that for some participants, talking about someone close to them with anorexia might be very emotional. All participants were provided through the information sheet with a list of support services and their contact numbers should they require them. Participants were aware that they could withdraw from the study at any time, without penalty.

### Data Protection and Storage

All interviews were recorded using a digital voice recorder. Once they were safely transferred to electronic storage audio recordings were deleted from the Dictaphone. Due to time restrictions, six transcripts were transcribed by a professional transcription service which participants had consented to. The external transcriber was bound by a confidentiality agreement in line with the University of Lincoln and this was signed and returned to the University prior to them receiving the audio files.

In adherence to the Data Protection Act (1998) all information and data will be kept confidential under secure storage at the University of Lincoln for seven years, after which it will be destroyed. Access to this information will only be available to the study author, Research Tutors/Academic Research Supervisors on the programme and administration staff at the University.

Identifiable data (e.g. consent forms) is stored in a locked filing cabinet at reception at the University of Lincoln. Anonymised data is

stored separately to identifiable data in a secure locked filing cabinet, in the Senior Clinician's room at the University of Lincoln.

### Confidentiality

To ensure anonymity, participants received a unique identification number and each participant was made aware that both they and the person that they discussed in the interview would be given pseudonyms to protect their identity. These pseudonyms were used for any quotes used from the data. Any references to personal information about the participant or the adult that they discussed was altered or removed from the transcripts to protect personal identity.

### **Qualitative Rationale**

A qualitative methodology is well suited to a research question that aims to explore a phenomenon in-depth and gather rich and detailed information. A non-numerical method was needed to capture the participant's perspectives of facilitating problem disclosure and help seeking in adults with anorexia

### Limitations of Qualitative Design

Often the critiques of qualitative approaches come from a different epistemological stance and apply inappropriate standards. A criticism of qualitative research has been that it lacks scientific rigour: lacking reproducibility and generalisability (Mays & Pope, 1995). Providing a detailed account of the method to allow replication, and documenting the process of analysis in detail, can increase scientific rigour of qualitative research (Mays & Pope, 1995). Smaller sample sizes are used compared to quantitative research so it is more difficult to generalise findings, but this is not always the aim of qualitative research (Marshall, 1996), as they tend to be more interested in gathering in-depth, detailed information about the subject matter (Miles & Huberman 1994).

Quantitative researchers have argued that qualitative research is subject to researcher bias with inadequate descriptions of the researcher's assumptions and method, specifically with regard to data analysis (Mays & Pope, 1995). However, some of these criticisms, such as researcher bias, could also apply to quantitative approaches, and these criticisms may be better argued as reflective of poor research, irrespective of whether a qualitative or quantitative approach was used. A further criticism of qualitative research is the view that "anything goes" (Braun & Clarke, 2006, p26). This view might be unreasonable as there are guidelines and criteria available for conducting good qualitative research. Braun and Clarke (2006) have provided a 15 item checklist of criteria for good thematic analysis which guided this study. The researcher is also encouraged to remain reflective throughout the research and be explicit about their own possible biases and assumptions and the possible influences of these on research design, collecting and analysing the data.

### **Study design rationale**

#### Semi-structured interviews

Semi-structured interviews are a widely used method of data collection in qualitative research because it is a method that is compatible with several methods of data analysis (Willig, 2008). Semi-structured interviews in this study lasted a mean time of 60 minutes. The interview schedule was based on knowledge of the topic area and reading of the literature.

The semi-structured interview combines aspects of the formal interview with specific roles of the interviewee and interviewer, with features of an informal conversation, with the use of open-ended questions. In this sense rapport can be built quickly, but has to be managed sensitively, as it can be easily affected by behaviours such as turning on the audio recorder which might serve to remind the

person that they are being interviewed (Willig, 2008). Although open ended questions in a semi-structured interview allow the interviewee more freedom in their response, it is the researcher's questions, prompts and comments that direct the interview to obtain the data that will answer the research question/s. The interviewer can also probe the interviewee to gain more information or elicit further details (Willig, 2008). In a semi-structured interview each participant's views are explored in depth. The experience of being listened too by somebody may feel therapeutic for the participant (Willig, 2008).

Consistent with the critical realist epistemology it is important to remain aware that what participants' report in the interview are not direct reflections of their thoughts on the subject matter. The context and meaning of the interview for the participant would have influenced what they said (Willig, 2008). In this study, parents, a friend and partner were all interviewed about someone close to them that they had supported to get help for anorexia. Their accounts were examples are how things are at this time for these individuals and that other people, including the person that they discussed in the interview, could hold differing viewpoints based on their own backgrounds, understandings and experiences. Furthermore, the primary researcher's experiences, beliefs, and social and cultural factors will have influenced their words in the interview (Willig, 2008).

Effect of interviewer social identities including age, gender and ethnicity may have not been applicable in this study, as nine out of 10 interviews were conducted via the telephone, so apart from gender, the other identities may not have been obvious. However, it is important that the interviewer remains aware that these factors can also have an effect on the interview.

### Telephone interviews and Face to face interviews

Face-to-face interviews are often seen as the “gold standard” in qualitative research and telephone interviews are largely neglected and seen as a less favourable substitute to face-to-face interviews (Novick, 2008). However, with mobile telephones so widely used nowadays, talking on the telephone is likely to be an ordinary experience (Carr & Worth, 2001; Novick, 2008).

Telephone interviews are commonly used in quantitative research for data collection. They can reduce cost and travel and provide the opportunity to recruit from wider geographical locations (Aday, 1996). Lack of visual cues is stated as the main disadvantage of telephone interviews (Garbett & McCormack, 2001). These result in a loss of contextual and non-verbal information which might affect rapport (Novick, 2008). Before the interview begins, speaking informally on the telephone to the participant (Burnard, 1994) and using verbal communication skills such as empathy and warmth (Tausig & Freeman, 1988) can help to build rapport on the telephone.

### Inclusion criteria rationale

As stated in the extended background and study rationale, help seeking in adolescents with anorexia has already been explored. As anorexia can become chronic the longer it is left untreated, and is associated with poorer recovery outcomes, the study focused specifically on adults, which was defined as those 18 years and over. A significant other was self-defined as it was acknowledge that this could be a range of people in the person’s life. Participants self-identified as parents, a partner and a friend.

As mentioned in the journal paper, four participants had tried to encourage the person with anorexia to seek help pre and post 18 years. As noted, at times they moved between ages in their

interview, so it was not always possible to clarify pre and post 18. However, there were some clear pre 18 points, such as the discovery of a problem. A decision was made to include these participants in the analysis because a strength of qualitative research is the ability to examine the full complexity of the psychological and social world as we encounter it. So although the interview focused on post 18, those who also had experience supporting someone with onset before 18 were included.

### Sample size justification

There are no concrete rules for sample size in thematic analysis (Baum, 2000). In qualitative research, small sample sizes are often used as the aim is to explore a phenomenon in depth and detail (Miles & Huberman 1994).

Published thematic analysis papers use a range of sample sizes, from ten participants (Goodier, McCormack, Egan, Watson, Hoiles, Todd et al. 2014) up to 60 (Joffe, 2012). Numbers may be a poor guide to sample size as it may lead to increased quality over quantity, and for a detailed analysis, high quality in-depth interviews should be privileged over quantity. This study aimed to recruit a minimum of 12 participants and up to 15, as it seemed achievable in a Doctorate in Clinical Psychology project. The final sample size of the study was defined practically, based on the time limits of the project and the number of participants who self-selected to participate.

### Recruitment

The study was advertised through several different means. Beat the eating disorder charity, provided a link to the study advertisement on their website under "Family and Carers". They also email details of research projects to people with eating disorders and carers who are part of their "research database". The researcher officer for Beat intermittently emailed the primary researcher to



inquire about recruitment and sent out a tweet towards the end of the eight month recruitment period to try and boost recruitment uptake. The primary researcher attended two different carer groups at a local eating disorder charity in the East Midlands to informally talk about the research. Participant information sheets were left with a clinician from the service. Another local eating disorder service that ran carer groups displayed the study advertisement in their service. Online, a link to the study advertisement was placed on a website for carers of individuals with an eating disorder, and circulated via email to members of a carer group that covered a large geographical location in the UK. All individuals interested in taking part contacted the primary researcher by email. Following this initial contact, information sheets were sent to potential participants.

#### Audit Trail

Consistent with a critical realist framework, the methodology section is as detailed and transparent as possible regarding the study procedure to ensure that the study could be replicated. A reflectivity journal was kept throughout the analysis, to document the rationale of decisions made. An extract from this journal is presented and discussed in the critical reflection section of this paper.

#### Limitation of study design

Interviews are a simple method of collecting data, but can also be more time consuming than other methods (e.g. completing a questionnaire). Responses to questions may be subject to recall and retrospective bias, with interviewees not remembering and recalling details accurately, or explanation for their behaviour might be different after reflection compared to how they felt at the time (Willig, 2008). As only the significant other was interviewed in this study, only their account of events was reported and the person with anorexia may remember events differently. However, this is duly

acknowledged and the purpose of the study was to only gather the perspective of the significant other.

Furthermore the data could be subject to self-selection bias, as the participants were self-selecting. Two participants were recruited via snowball sampling through two individuals who took part. Snowball recruitment was useful for identifying further suitable participants. However, the potential drawback of this method of sampling is that recruited participants are likely to be from the same social network (Hennink, Hutter & Bailey, 2011) but their experiences could still be different.

### **Epistemological Position – Critical Realist**

Epistemology refers to a branch of philosophy that considers what knowledge is and how it is gained. A critical realist framework (Cook & Campbell, 1979) was adopted for the study, that focuses on the individual's meanings and experiences, whilst remaining aware that all knowledge gained is local and context specific (Madill, Jordon & Shirely, 2000). It contends there is not one pre-eminent method of knowledgeable discovery and instead argues that there are multiple paths to the truth.

It is acknowledged that there might be a truth to be discovered, but the participants in the study will experience and give meaning and understanding to events, in light of their own backgrounds (including gender, time, place, culture, and religion) and experiences. Additionally, this position acknowledges that the participant's account of their experience will be interpreted through the author's own background and experiences.

## Other Epistemological Positions - Positivism and Social Constructionism

At one end of the continuum is positivism. Positivists believe that it is possible to accurately describe the world. From this epistemology the aim of research is to produce objective knowledge. The researcher is seen as detached and their own biases are not considered to affect the research (Willig, 2008).

At the other end of the continuum is social constructionism which argues that what we see and experience must be understood in context (Willig, 2008). From this position the world cannot be objectively described. It is recognised that we use language to construct our views of the world, and knowledge is not fixed, but it is fluid and bound by time and culture (Burr, 2003). From this position there is no one objective 'truth' out there to be revealed, but multiple versions of the 'truth'.

## **Qualitative Methods**

### **Overview**

Three different qualitative methods commonly used in qualitative research will be outlined below together with a rationale for not using them for this study. Following this a rationale for using thematic analysis and a critique of this method for data analysis will be discussed.

### **Alternative qualitative methods**

#### Grounded Theory

Grounded theory explores social processes and meanings with the intention being to develop a new theory. Such theories are specific to the context in which they are developed and "grounded" in the data (Willig, 2008). Similarly to thematic analysis, grounded theory can be used with a range of epistemologies. This method is

particularly useful when there is no existing theory, or when looking to expand and develop an existing theory. There is some overlap between thematic analysis and grounded theory such as aiming to find patterns in the data (Braun & Clarke, 2006). Grounded theory was not used in the current study as the aim was to explore experience and not build a theory. Within the time scale of a DClinPsy project it was felt it was not possible to develop a fully saturated theory.

### Interpretative Phenomenological Analysis (IPA)

IPA is used to explore in detail how participants make sense of their personal and social world. IPA is particularly interested in the meaning that particular experiences hold for individuals. IPA is theoretically bounded to phenomenological epistemology (Smith, Jarman & Osborne, 1999) and involves detailed examination of the person's lived experience in order to further understand the subject matter (Braun & Clarke, 2006). The aim is to explore the person's personal experience, as opposed to reporting an objective account of it, but recognises that this is a two stage process. The participant makes sense of their world, and then the researcher makes sense of the participant's interpretation of their world (Smith & Osborn, 2008).

IPA was not used in the current study because the research question is not exclusively interested in phenomenology. The research question also refers to actions and what people do in response to actions, and so a method with a broader focus was required.

### Discourse Analysis

Discourse analysis examines language in use, and is interested in the construction and function of language. In this approach language is seen as a form of social action (Wetherell, 2001). This method also considers the social context of language: people's

positions in society and power relations. Discourse analysis was not used in the current study because the study aims were to explore experiences and actions rather than analysing language and what participants are “doing” with their words (Willig, 2008).

### Rationale for Thematic Analysis

Thematic analysis was used because it fits with the aims of the study and is useful for identifying themes across the data set.

Secondly, thematic analysis is not devoted to a single philosophy of science, but can be employed in a range of epistemological positions. It can therefore be used within a critical realist framework.

### Critique of thematic analysis

One of the strengths of thematic analysis is it is deemed simple to use and so might be useful for novice researchers new to qualitative research. A further strength, which is also deemed a weakness, is its flexibility, because what can be said about the data is very broad and therefore it has been criticised that almost anything could be classed as theme (Braun & Clarke, 2006). However, there are guidelines for conducting thematic analysis and an ongoing debate about what constitutes a theme (See Braun & Clarke, 2006). It has also been questioned whether thematic analysis is a qualitative method in its own right or a tool that is used across all qualitative approaches (Boyatzis, 1998). However Braun and Clarke (2006) address this question in their paper and conclude that it is a method in its own right.

## **Analysis**

### Prior decisions

Based on the recommendations by Braun and Clarke (2006) some prior decisions were made before the analysis and these are discussed below.

### A rich description of the entire data set or a detailed account of one aspect

The first decision was about whether to provide a rich thematic description of the whole data set or a detailed account of one part. For this study, the analysis focused a rich description of the entire data set because that represented all of the participants' views, which was felt particularly important because little is known about the topic area.

### Inductive or theoretical thematic analysis

Themes within the data can be identified in two ways; inductive or deductive. An inductive approach is when the themes are linked to the data themselves (Patton, 1990) and "the data has not been coded to try and fit it into an existing coding frame" (Braun & Clarke, 2006, p.12). Alternatively, deductive thematic analysis is theory driven (Braun and Clarke, 2006). When designing this study, a prior decision was made that the themes would be identified in an inductive manner. However, a mid-range theoretical position was taken in the analysis, or "hybrid" approach (Feresay & Muir-Cochrane, 2006) which incorporates inductive and deductive approaches. This was because whilst the primary researcher sought to be inductive, it became clear during the analysis process that some data mapped onto an existing theory and so a decision was made to map it onto this theory. Whether a researcher can be purely deductive is a contested matter. Braun and Clarke (2006) highlight that although the researcher may aim to be inductive, they cannot completely detach themselves from what they already know when analysing their data. Whilst recognising this, the aim of this study was to code the data with an open mind, using reflection and supervision to aid this.

### Semantic or latent themes

The last decision was around the “level” that themes were identified: semantic or latent (Boyatzis, 1998). A semantic level is where the themes are identified simply at the descriptive level. A thematic analysis at the latent level is more analytical than semantic and starts “to explore the underlying concepts that are informing the content of the semantic the data” (Braun and Clarke, 2006, p.13) and explore the wider meanings and implications of the patterns (Patton, 1990). In the current study, data was analysed at the latent level. An example of the coding procedure can be found in Appendix I.

### Data Analysis

There were several steps to analysing the data which was completed manually and guided by Braun & Clarke (2006). Initially the entire data set was actively read and re-read to gain familiarity with the data. Meanings and patterns were searched for and any initial thoughts were noted. Secondly, across the entire data set, initial codes were generated in a systematic manner. Data was collated relevant to each code. A code was a word or few words that captured the essence of the sentence. (A worked transcript can be found in Appendix J). This step generated codes at the semantic level. From here codes were analysed further into categories at the latent level. Categories were then amalgamated into potential themes, with some forming overarching (superordinate) themes and some subthemes. A short description of each theme was then written which helped the primary researcher to identify any overlap between themes. Themes were then reviewed to check that they accurately represented the data set. Once the themes had been clearly defined and refined, they were named (Braun & Clarke, 2006).

### Saliency Analysis

Braun and Clarke's (2006) paper on thematic analysis addresses the question of what should constitute a theme in thematic analysis and this question is a contested concept. Buetow (2010) discussed how the method conflates two concepts – recurrence and importance. More specifically, high prevalence of a theme does not necessarily equate to high importance and similarly, low prevalence does not necessarily mean a theme is not important. Buetow (2010) suggests that themes can be arranged into four categories; "1) highly important and recurrent, 2) highly important and not recurrent, 3) not highly important but recurrent and 4) not highly important and not recurrent" (Buetow, 2010, p.124). However, Braun & Clarke (2006) advise flexibility and researcher judgement in concluding themes of meaning. Therefore, in this study, we defined a significant theme as a combination of recurrence across transcripts, relevance to the research question and having potent implications for clinical practice.

### Credibility check

This study used Braun and Clarke's (2006) 15 point checklist for good thematic analysis as an evaluation criteria because it was specific to the methodology used. How this study aimed to meet the criteria can be seen in Table 6.

### Personal Reflection

In line with a critical realist perspective it is important to maintain transparency and part of this includes highlighting any pre-assumptions held as a researcher. When this study was conducted, the primary researcher was a 30 year old female trainee clinical psychologist, who had no personal experience of an eating disorder.

Data analysis was discussed with the primary supervisor, and the second supervisor also reviewed initial coding and categories.



Supervision helped to draw the primary researcher's attention to any potential biases. As an example, the primary researcher amalgamated some initial codes into a category which was labelled "carers approach". When discussing the coding in supervision their attention was brought to the use of the word "carers" and the meanings attached to this label. It was recognised that maybe not all participants would have defined themselves as "carers". This helped to remind the primary researcher to think carefully about the language that was used to name codes, categories and theme.

Table 6

*15-Point checklist of criteria for good thematic analysis process from Braun & Clarke (2006)*

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<b>Process</b>	<b>No</b>	<b>Criteria</b>	<b>How this study met the criteria</b>
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for "accuracy".	Data was transcribed verbatim and checked against recordings for accuracy.
Coding	2	Each data item has been given equal attention in the coding process.	Initial coding was conducted on every transcript. These initial codes were all analysed further into categories.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.	Themes were generated on the basis of reoccurrence across all transcripts and relevance to the research questions.
	4	All relevant extracts for each theme have been collated.	This was conducted in excel: under each category was all the relevant codes from each transcript.
	5	Themes have been checked against each other and back to the original data set.	Themes have been checked against the original data set, and revised and refined through discussions in supervision.
	6	Themes are internally coherent, consistent, and distinctive.	Themes were refined and discussed in supervision.

Table 6  
*15-Point checklist of criteria for good thematic analysis process from Braun & Clarke (2006)*

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Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.	Initial descriptive codes were further analysed into categories.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.	This point guided the presentation of results.
	9	Analysis tells a convincing and well-organised story about the data and topic.	The themes reflect a sequential process.
	10	A good balance between analytic narrative and illustrative extracts is provided.	This point guided the presentation of results. Drafts were read by supervisors.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.	Time to conduct the analysis was scheduled into the time plan.
Written Report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.	This is reported in the extended methodology.
	13	There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent.	The method was detailed and transparent to illustrate this.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.	This point guided the write up and presentation of results.

Table 6

*15-Point checklist of criteria for good thematic analysis process from Braun & Clarke (2006)*

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15	The researcher is positioned as <i>active</i> in the research process; themes do not just “emerge”.	In line with the epistemological position adopted in this paper, it is acknowledged that the researcher is an active part of the data analysis.
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## Results

Table 7 below illustrates all of the themes and subthemes of the study.

Table 7  
*Superordinate themes and subthemes*

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First Response
Confrontation and Confession/Denial
Stepping In
Informational support
Practical support
Emotional support
Cognitive Support
Stepping Back
Care Context
Seeking help
Definition of recovery
Experience of services
Flexible and Persistent approach
Self-care
Unsuccessful attempts

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The following themes: (1) Care Context and (2) Flexible and Persistent Approach could not be included in the journal results section. These themes are about the wider context around the main themes that are reported in the journal paper. The themes and their subthemes will be discussed below. The section will finish with an extension of the theme stepping back which could not fit in the journal paper due to word limitations.

### **Care Context**

The care context refers to the wider system around participants in understanding their actions to try and encourage the person with anorexia to seek help. The actions that participants took were a product of the participant, the person that they were trying to get to

seek help and the wider context, in terms of services and what help was available. The accounts that participants gave of their actions could not be understood without understanding the wider context, specifically, how the system responds to their efforts. This theme has three subthemes: seeking help, definition of recovery and experiences of services.

### Seeking help

Participants' actions in the study were aimed at encouraging the person with anorexia to seek treatment. What participants reported was that the process of seeking help was not a linear and straightforward process, but a much more complex and circular process. Eight participants reported that the person with anorexia sought help at some point. Some participants reported that the person with anorexia saw a variety of different people; including psychiatrists, counsellors, therapists, dieticians, cognitive 'hypnotherapists' and psychologists, sometimes reporting that the person was seeing several different helping professionals at any one time.

The majority of participants reported that the person with anorexia dropped out from treatment before it was complete. Some participants reported that they felt that the person with anorexia would be compliant with treatment in services so that they could be discharged and could return home, only for the cycle of under eating to begin again. In the quote below Sally described feeling frustrated that Claire's compliant behaviour when she sought treatment misled staff into believing that she was recovering:

*(Sally) "And the thing about Claire is, whenever she is in treatment. She will just do exactly as they say and be very amenable, and you know, erm, and they will think "she is so compliant, we can trust her to go home"."*

Five participants described how the person with anorexia engaged in a process of continual engagement and disengagement with treatment during the time that they supported them. Jo described the cycle that the person she supported to seek help became stuck in. From her account it seemed that when the person sought help, they were forced to because of their low weight and powerless to resist treatment because they were detained under the Mental Health Act. It seemed as soon as their weight began to increase and they were no longer physically too weak to resist treatment they were keen to be discharged, and the cycle started again once home.

*(Jo) "She knows that if she gets below a critical mass, that they can use mental health powers and section her, they've sectioned her twice already...The same thing happened, she gets, you know, within three months, she puts a little bit of weight on, she starts to look better and she starts to talk to them about taking—wanting to be discharged and comes home and it's the same pattern."*

Few participants reported more straightforward experiences of the person with anorexia engaging in help. Two participants reported a sudden moment where, seemingly out of the blue the person engaged in help. Diane talked about this "Eureka" moment:

*(Diane) "And I went along on the 13<sup>th</sup> of February and walked in, after she had had a preamble with the dietician, and she said, "Mum, I've decided I think it's time that I started eating and I need your help and Hayley's help, the dietician, to help me do that, and that was it...The psychologist talked of it as a Eureka moment that occasionally happens. And that's actually the only way that I can describe it."*

### The definition of recovery

When some participants spoke about the person with anorexia seeking help, the belief of whether this had led them to recover was ambiguous, because participants' accounts of the definition of recovery from anorexia was unclear. The term "recovered" appeared to be used very cautiously, and instead participants reported more tentatively that the person was "*trying to get better*" (Sally) or that person was on the "*plateau of recovery*" (Linda). Other participants reported that they felt the person's problems were still ongoing. What appeared to have led to these inconclusive comments about recovery was that even if weight had been stabilised through treatment, participants reported that this did not mean that there was no longer a problem and the person was recovered. Some participants reported that although weight improved, restrictive eating habits remained, the person's functioning was still affected, or underlying emotional problems had not been resolved. Kate described how despite her daughter making some improvements through accessing treatment, the underlying problem had not been resolved:

(Kate) *"It had the good outcome in the sense that they gradually got her up to weight and they introduced her to CBT and things. Erm, and she's made friends that she's kept from there. Erm, and it was, it was, erm, I think, you know, you'd say it was a positive experience, but we haven't got to the root of it."*

This raises the question about when people will know that they have done enough to encourage someone to seek help and feel able to stop, what signs will they be looking out for that makes them feel that they can withdraw?



## Experience of services

Experience of services is the participants' reports of the care system that they encountered. Six participants reported poor experiences of services for several reasons. Firstly some reported that service criteria based on body mass index was a barrier to entry for some of the people with anorexia. Helen highlighted a possible gap in the services that she encountered for treatment for mild to moderate anorexia:

*(Helen) "Because I know, if their weight isn't that bad, it's actually quite hard to convert to adult services, adult NHS services. Because again, they're completely overloaded and because her weight wasn't has never — and she wasn't on the emergency list and was actually functioning quite well, until she had a mental meltdown."*

Service criterion around engagement was reported as another problem. From participants' accounts, the process of getting someone to seek and stay in help was difficult, but when faced with a rejecting care pathway, this could be potentially harmful. Sally spoke about how a service criterion around engagement was a barrier to the person seeking help:

*(Sally) "She went back and they said they were going to discharge her because she wasn't – because they couldn't help her, because she wouldn't allow them to help her and there were other girls that needed the help."*

Jo recognised that her daughter was difficult to engage, but commented that for those that are, there doesn't seem to be another option for them:

*(Jo) "Sarah is probably one of these hard to reach, in mental health terminology, this non engager or this person who won't accept help. But I can't somehow reconcile that, erm, in terms*

*of, you know, there just doesn't seem to be a pathway to support people with anorexia really."*

Debbie described how the services' method of engaging people was by telephone and this did not match her daughter's needs, and she was consequently discharged because they did not offer any other methods of contacting someone for an initial appointment:

*(Debbie) "So basically, they just dropped her because their policy was, erm, if someone didn't respond after three phone calls, then they took them off the list, erm. And she doesn't speak to people on the phone anyway actually, Faye, you know, she just texts people, but she doesn't like to have telephone conversations. So she was dropped from that, erm, and kind of fell by the wayside."*

Not all encounters with services were poor. Kate reported that services played an important role in her daughter's journey of recovery. However, she also reported that the impact of the long waiting times for NHS treatment was made worse when no alternative treatment options were suggested to them. It seemed to be a missed opportunity to capitalise on someone's motivation, which in this population appeared to be transient:

*(Kate) "The National Health were so good and pulled her through and got her through, erm, and were very, very good, and there's no doubt about that. But in fact, when she went back to them, they could only, they couldn't offer anything for about a year. And I think at that stage, it would have been helpful if they had said, look, you know, another option is to go privately. Because it seems almost that the National Health won't do that, even though they can't actually provide, erm, at the time. And I think, erm, we might have, the fact that she went for help was a good opportunity to, erm, to, erm, to be*

*proactive. And waiting a year and, it's just, it rather consolidates the bad feelings."*

Others reported poor experiences because of long waiting lists in the NHS, and a lack of alternative options being offered to them if they did not want to wait for NHS treatment. The majority of participants in this study reported that due to the long waits for NHS service they sought out and tried to encourage the person to seek private treatment. Participants reported being keen to act fast and not wait which seemed to be fuelled by their worries about the person's low body weight and the consequences of this. Linda arranged help for her daughter to bridge the gap between seeking treatment and waiting for the referral to be accepted:

*(Linda) "I mean first of all, I think immediately, she was happy to go to a therapist and we arranged for her to see a therapist, privately, while we were waiting for the referral. The referral took five or six months."*

Another part of participants' experiences of services concerned the policy of confidentiality. Four participants described how the policy of confidentiality and not sharing information with parents once the person was an adult made their efforts in trying to encourage the person to seek treatment more difficult. In four cases, the participant had tried to encourage the person to seek help for anorexia pre and post 18 years. Some of these participants reported that they experienced a clear change from being involved and knowing everything around the help seeking process, to being completely cut off and excluded, and this was difficult. Diane commented on the changes she experienced around being involved once her daughter turned 18 years. She reported that once her daughter turned 18 it seemed to be assumed by services that she would not want her parents to be involved in her care anymore and suddenly being cut off was very difficult:

(Diane) *"It's almost as if, when she was seventeen and three hundred and sixty four days she was a child and I was involved in things, and when she was seventeen and three hundred and sixty six days, suddenly no one would talk to me anymore. And I felt that at the transition between child and adolescent, a really important thing that could have been done, would have been, 'Beth, would we have your approval to continue to involve your parents in your care?' And at no point was that ever done. And so she went to this adult unit, which she ran away from. And no one ever, no one returned my calls initially, no one wanted to involve us in any shape or form."*

Although they found the policy of confidentiality frustrating, these participants reported that they continued to try and encourage the person to seek help. Debbie, however, reported that she struggled with this exclusion and asked her daughter to write a letter stating that she could speak to the GP:

(Debbie) *"It was much more difficult to, erm, engage, for me to engage with any services without having Faye's consent, obviously, because she's an adult. So, so I actually did end up getting her to write a letter to say I could speak to the GP on her behalf."*

Feeling excluded was not only experienced by participants who had experience supporting a person with anorexia pre and post 18 years. Jo reported that her daughter did not want her to attend appointments with her because she was an adult. She described the difficulty of supporting an adult with anorexia who has capacity and the right to live their life as they want to:

(Jo) *"She doesn't want me to go and she doesn't think she's a child and she doesn't think that we should be there. So half the time, does she go, we don't know, erm, because she's twenty*

*six years of age. And she's an adult, erm, to all intense and purposes, she's got capacity and it's OK for her to live like this, you know, and that's the situation isn't it really."*

Feeling excluded by services was not experienced by everyone. Sue who only had experience supporting an adult with anorexia felt included by the GP at appointments that she attended with the person:

*(Sue) "This doctor every time she asked Hannah a question, she's ask it to Hannah and then turn to me and say, 'what do you think about that?' And "Are there any other questions that you have?" And she was really supportive to me as well."*

Helen reported that she did not experience feeling excluded by services once her daughter was an adult, and reported that she was given the option by professionals to be included:

*(Helen) "There was no resistance to me coming in and the nurse wasn't saying, 'Oh, she's 18 mother shouldn't come in.' She was saying, 'Come in mum.' [laughs]. 'Let's here what you've got to say, as well'".*

### **Flexible and Persistent Approach**

All of the participants in this study were active and persistent in their efforts to try and get the person with anorexia to get help. These participants persevered, and although it might be questionable whether the chaotic combinations of care that some of the people with anorexia ended up receiving were the best, the participants' efforts cannot be denied. Many participants were flexible in their approach, trying different methods of support as discussed in the journal paper, and modifying their own behaviours in order to try and encourage the person to seek help. Within this theme were two subthemes; self-care and unsuccessful attempts, and both are described below.

## Self-care

This subtheme is about the impact that trying to support the person with anorexia to seek help had on the participant and how they managed this. Six participants discussed the impact of trying to support the person with anorexia to seek help had on their own wellbeing. Participants described the process as time consuming, stressful, difficult, "draining" (Helen) and at times "hell on earth" (Sally). Some participants spoke about how the process of supporting the person to seek help became the main focus of their relationship with them. Sue described how the eating disorder consumed every part of their lives and relationship:

*(Sue) "I mean from the point at which I came back, everything became about the eating disorder. So, we would talk about it at every meal time, every other time, like I emailed during the working day, like all the time. So everything revolved around that."*

Other participants spoke about how they felt frustrated at times and helpless in trying to encourage the person to seek help. Some spoke about the loss of the person that they had known before the anorexia had taken them over. Jo compared anorexia to dementia, and spoke about the difference in the person before they left for University and the damage caused by the anorexia:

*(Jo) "It's like dementia in a young person, is the only way I can describe it, you know. She went away a young bright effervescent bubbly, very confident, very outgoing person, comes back as somebody who is, you know, cognitively impaired."*

The impact that supporting the person with anorexia had on the participants own wellbeing had to be managed to allow them to be able to continue to support the person with anorexia to seek help.

Some participants reported that they engaged in some self-care techniques to help them manage. Three participants reported that they sought therapy for themselves as a result of supporting the person to seek help, and two reported that the family engaged in family therapy. Sue reflected that she had neglected her own self-care as she had been so preoccupied supporting the person with anorexia, and she described feeling almost hypocritical encouraging someone to get help without acknowledging her own need for support:

*(Sue) "I think I would have got myself support, sooner. Cause I, I had therapy myself, just to help myself deal with it all, and I put that off for a really long time, because it until I should have needed it because I think it (inaudible) before we really properly addressed it and for someone who was going on to get therapy for so long for Hannah, I think I should have probably taken a bit of that advice as well."*

Jill spoke about how talking to others with shared experiences was a source of support for her when she found things difficult. Attending carer groups and getting the opportunity to talk to others about how they were coping helped her to manage:

*(Jill) "Well you have to find some kind of way of supporting or finding your own kind of, you know, through it...I think carer support groups are helpful, erm, because you're talking to other people who are in a similar situation. I went to, erm, a carer's conference, erm, another one, a workshop actually, kind of about, erm, six weeks ago. And it was quite helpful, but it was actually meeting other people, and talking to other people about how they're coping."*

Jo and Sue reported how their outlook helped them and they tried to remain hopeful even when times were difficult:

(Jo) *"I mean every time she's gone to hospital I've thought, you know, like you think, 'oh maybe this time this is going to be it'."*

(Sue) *"I was always thinking, 'maybe now'. I think, after that time, I thought, 'Surely'."*

One participant reported that they engaged in self-care by keeping a book of positives, remaining hopeful, and trying to see the condition as separate from the person. Focusing on the small positives helped the participant below to see that their efforts were worthwhile:

(Helen) *"I used to keep a box, not a box, a book of positives. A little notebook and if a positive thing happened in the day, no matter how small, I wrote it down. Because as a carer you can so easily feel that nothing is happening and yet each tiny little positive, cumulatively, working towards something bigger."*

### Unsuccessful attempts

This subtheme represents the ways that the participant made sense of their unsuccessful efforts in trying to encourage the person with anorexia to seek help. What participants reported was that it was not the attempts themselves that did not work (although as discussed in the journal paper, direct and forceful approaches were reported to be unhelpful), it was the place that the person was.

Six participants spoke about the person being in denial of a problem, or that the negatives of anorexia were not enough to make the person want to change. Jill spoke about how for a while she thought that her daughter had just not built a good therapeutic relationship with the professionals that she had seen, and that it took her a while to realise that these were just excuses for her not wanting to engage in treatment:



(Jill) *"All this, all this, you know, "my GP, she's just not sympathetic, she just won't listen to me and the nutritionist was no good and she was saying rubbish". What I should have picked up was, actually, the problem was Marie. In the middle of it she was in denial about what was happening to her and, therefore, rejecting everything that was being suggested."*

Helen spoke about how her daughter said that she no longer wanted to engage in treatment because she was tired of repeating her story to professionals. Helen reported that her daughter was aware of what she needed to do to change, but that she was not at the stage of wanting to change her behaviour:

(Helen) *"No! No! leave me alone, leave me alone". So she's in the mode of I don't want to — at one point she just said to me, "Mum, I'm sick of telling my story to these people. I know what to do."*

Kate blamed herself for managing the condition too well at home, and understood this as actually preventing the person with anorexia from seeking "professional" help:

(Kate) *"I tend to pop her in the car and drive her back. And she goes in relatively, you know, comfortable, compared with how she arrived with us. So this thing is quite useful but again, you wonder if she didn't have that, whether it would prompt a crisis and she would go and get some more proper help because I'm not proper help."*

Unsuccessful attempts or rejection of their efforts by the person with anorexia, did not stop these participants from still trying to encourage them to seek help. Jo reported that when the person with anorexia informed her that she was going to discontinue CBT, she tried to encourage exploration of other options:

(Jo) "I was in work and she rang me up and she said, "Oh I'm not going to see Kathy anymore because I don't think that therapy works for me". So I said, "that's OK, erm, CBT's just one of the range of many therapies that are available"."

Over half of the participants spoke about their difficulties in trying to encourage the person to get help. Helen described how she would suggest options for treatment and then leave it a while before approaching it again:

(Helen) "I sent Emily the link to this girl and she said, "Ohh yeah, it looks interesting" and I said, "Well, it's an alternative for anytime that you're ready." And she'd go, "Yeah, yeah, that's really interesting". And then a couple of weeks later, I'd say "Hey Emily, have you thought about that?" "No, I'm not going!" [laughs] you know, so it was all that."

Four participants reported that they felt their efforts to help the person to seek treatment were completely dismissed and refuted. Diane described how she felt she could not get through to the person with anorexia. She uses the word 'alien' as a metaphor for illustrating how her efforts to communicate were not getting through and had no impact:

(Diane) "I would say her nightmare period was from about August through to maybe the end of October. And during that stage, I just simply could not get through to her. It was as if I had an alien being living in my house. And I would say maybe, sort of, from --, she would listen to what you had to say, but then would just basically do whatever she wanted to do."

Diane reported that when her efforts were dismissed she still continued to be involved. She reported that she tried to discourage what she perceived to be unhelpful behaviours, such as daily four miles walks and contacted the person regularly to ensure that she

was safe. She then reported speaking to a friend who encouraged her to step back (reported in the journal paper) and she tried to modify her behaviour to be less direct and more calm and compassionate. Stepping back allowed Diane to frame the person's behaviours as symptoms of the condition as opposed to deliberate choices:

(Diane) *"She wasn't doing it to piss me off, she wasn't doing it because I was a bad mother or because --, she was seriously, seriously mentally very, very, very ill."*

Helen reported that the person with anorexia could be verbally abusive and completely dismissive of her efforts to try and support them to seek help, but that she continued to try. Helen reported experiencing a noticeable change in supporting her daughter pre and post 18 years, in terms of how her efforts to support her were received. Helen described that pre 18 years, her daughter was more accepting of her efforts to help her, and engaged in treatment at times. However, she reported that once her daughter turned 18 years old, there was a change and she completely disengaged from treatment and refused to engage in any further help suggested by her mother. Helen described that once her daughter turned 18 years old she became aware of her rights as an adult and recognised that this could directly impact on the level of involvement that her mother had:

(Helen) *"Probably June, no May, end of May last year, was the last time she saw any professional. So from the age of 18 she was like well, pardon my language Sam, but she was like, "Fuck you mother" she did use those words [laughs] so being quite abusive, "I'm not doing it"."*

### Stepping back (extension of theme reported in journal paper)

The point of qualitative research is to present findings in their context, so “stepping back” as a strategy in help seeking (as reported in the journal paper) is a part of a wider strategy of stepping back in other ways too. In talking about stepping back, five participants spoke about stepping back from trying to force the person to eat. These participants’ reported that early on in their approach they tried to encourage the person to eat more and this seemed to be fuelled by fear for the person’s health. However, over time they reported that trying to get the person to eat more did not work.

Jill spoke about how the fear of her daughter’s low weight led her to confront her about eating more, even though she had some doubt that it was not going to work:

(Jill) *“I mean the more confrontational, right you’ve just got to eat, you know, clearly doesn’t work. And I kind of knew it wouldn’t work and I knew it was stupid. Like you sometimes find yourself doing these things just because — just because on the outside sometimes it seems so simple.”*

Diane spoke about pleading with her daughter to eat; perceiving that initially she had a choice and was choosing not to eat. However, over time and through advice, Diane spoke about how she changed her approach. Understanding more about anorexia helped her not to take her daughter’s actions personally:

(Diane) *“And I saw that me begging and pleading and Beth, “if you can’t eat for yourself, if you love your mother do it for me. If you love your grandma do it for her”. That wasn’t working because I was the enemy trying to force her to eat. And so actually, overnight I changed, I changed my approach and went from this screeching haragon to actually*

*being this very calm person who saw that my daughter wasn't doing this to bug me, she wasn't doing it to rebel."*

## **Discussion**

### **Overview**

The extended discussion will begin by discussing the results reported in the extended paper in relation to existing research. Clinical implications and suggestions for future research will be discussed in light of these findings. Some further strengths and limitations of the study will be reported in this section and it will end with a critical reflection of the research process. Some points made in the journal paper discussion are expanded on in this section. Where comments relate to material in the journal paper this will be made clear.

### **Summary of findings**

This study aimed to report central themes in this sample which might inform directions for further research, rather than make generalisable claims about the role of significant others in help seeking in adults with anorexia. Although, some findings echoed those of previous research, suggesting credible thematic conclusions have been drawn.

This study makes four novel contributions to our understanding of the role of significant others in problem disclosure and help seeking in adults with anorexia. Firstly, some significant others were able to initiate problem disclosure in adults with anorexia. Secondly, significant others became knowledgeable in trying to encourage the person to seek help, drawing on a range of resources. Thirdly, more direct approaches in helping the person were unhelpful and so participants stepped back in their approach over time. Lastly, participants offered a range of different methods and support. The first three contributions have already been discussed in the journal paper. The last one will be discussed here.

The themes reported in the extended results captured the following: Most participants' accounts of the care system that they encountered was that it was poor, with long waits for NHS treatment, service criteria and policies acting as a barrier to access, and little information provided about alternative options. The majority of participants reported that the person with anorexia did seek help at some point along the process, but that drop out from treatment before it was completed was high. Participants were active, flexible and persistent in their efforts to support the person to seek help and some reported that they took steps to manage their own self-care. Unsuccessful attempts to help the person with anorexia seemed to be perceived as a result of the place that the person was in as opposed to the method of support.

#### Implications of findings for extant empirical literature

Participant's reports of the care system that they encountered were that it was poor. Some reported that some of the persons with anorexia struggled to get access to treatment when their body mass index (BMI) was not low enough. The importance of early intervention and prognosis have been highlighted in the introduction and it seemed that for these participants early intervention was recognised as necessary, but was not available. This seemed to leave a space that significant others in this study chose to occupy. Whilst this finding might have been specific to the geographical location/s of participants, previous research has found that one of the barriers to seeking help for an eating disorder was a belief that the condition was not serious enough to require treatment (Cachelin & Striegel-Moore, 2006). With anorexia it seems difficult to get the person to seek help anyway because of its ego-syntonic nature, yet being told that they do not meet the criteria to access treatment may prevent them from accessing support again.

Some participants reported that being excluded from the person's treatment due to confidentiality made their role in supporting them to seek support more difficult because they were unaware if the person was engaging or even attending treatment. Although post 18 years, there are limits to confidentiality, the NICE (2004) guidelines for anorexia recommend that most individuals with anorexia should be treated as an outpatient and that inpatient treatment or day patient treatment should be considered for those whose symptoms have not improved with outpatient treatment. Given this recommendation, it places responsibility for care onto significant others (Zabala, Macdonald & Treasure, 2009). Therefore, it might be useful to consider including significant others more in the treatment of adults with anorexia, with permission of the person with anorexia. Significant others might be able to support the work being conducted in treatment, such as adherence to meal plans and so forth, as the participants in this study showed themselves to be active and committed to supporting the person to seek treatment and recover. However, there might be some dilemmas for significant others and services achieving this, given that people with anorexia can be secretive and in denial of a problem (Vandereycken, 2006). Information could be provided to carers about signs that might indicate that the person was not adhering to treatment plans and support for self-care might need to be offered as participants in this study commented on how difficult supporting someone with anorexia to seek treatment could be.

The majority of participants reported that the person with anorexia did engage in treatment at some point, but that it was common that they dropped out before they had completed it. It is widely recognised that drop out for treatment is high for people with anorexia and a high proportion of people do not complete the full course of treatment (Wallier et al., 2009). Individuals that drop out of



treatment are more likely to have poorer outcomes in the long term and less likely to recover independently (Beumont Russell & Touyz, 1993; Pike, 1998). The finding from this study illustrates that drop-out can be high even when significant others are involved. Therefore, it might be useful for significant others to be informed about what their role might be in supporting someone to seek help and what impact they can be expected to make. Services might inform their expectations through providing information via a group or leaflets about anorexia, which could include information about the course of anorexia and the commonality of early drop-out from treatment. This might help carers to be prepared and not set themselves unrealistic expectations in supporting someone. Previous research has found that dropout rates are highest in purely educational interventions, intermediate for one to one psychotherapy interventions and lowest rates have been found in family therapy trials. These interventions have tended to include adolescents with anorexia and not adults (Dejong, Broadbent & Schmidt, 2012). If the same held true for adults with anorexia, it would stand to reason that therapeutic approaches would be best to include significant others to reduce drop-out rates in treatment.

There was lack of clarity expressed by participants about what might constitute the person being recovered from anorexia. This study did not seek views on recovery and the finding was unexpected. but was interesting because it led the primary researcher to think about how significant others would know when they had done enough in supporting the person to seek help. If the person seeks help but then some symptoms remain, would they continue to try and encourage them to seek more treatment? This unclear definition of what constitutes recovery in anorexia is widespread and existing definitions are inconsistent (Hardin, 2003). Commonly recovery has been defined objectively through behavioural outcomes such as

weight restoration, improved scores on psychometric measures and absence of symptoms (Weaver, Wuest, & Ciliska, 2005). Other research that supports the lack of consensus in the literature about what might constitute recovery from an eating disorder, makes the point that recovery should include physical, behavioural and psychological components (Bardon-Cone, Harney, Maldonada, Lawson, Robinson, Smith et al. 2010).

In the current study some participants reported that when the person increased their weight through treatment it did not mean that they were recovered and underlying problems persisted. This supports the findings of a meta-synthesis study on first person accounts of recovery from anorexia (Cox & Rennoldson, 2013). Addressing weight alone has been termed “pseudo-recovery” (Kaski-Rahkanen & Tozzi, 2005), where the individual appears to have recovered, but actually underlying problems remain. Another study also found that participants who had recovered from an eating disorder, reported that a focus on weight in treatment was unhelpful. The person still required support, even when their weight had increased. Support only received when they were underweight seemed to reinforce to them the importance of weight (Linville, Brown, Sturm & McDougal, 2012). This finding might have implications for significant others in terms of making them aware that gaining weight may not be the goal of treatment and does not in and of itself indicate recovery. Information for carers needs to include information about the varieties of recovery that may be possible for people with anorexia and advise them on whether a person might need further assistance.

The study found that this group of participants were persistent and flexible in their efforts to support the person. Participants reported that supporting the person to seek help was a difficult, consuming and draining process and had an impact on their own

wellbeing. Most reported that they utilised self-care techniques to help them when they found it hard, such as personal therapy or trying to remain hopeful. These techniques helped them to remain open and flexible to different approaches such as the advice to step back. The study findings support those of previous studies that reported caring for someone with a mental health problem can cause you to feel strong emotional reactions (Zabala, Macdonald & Treasure, 2009). A lot of the research on carer burden has focused on schizophrenia with little other diagnostic categories having been explored (Schulz & Rossler, 2005). However, one study found that the levels of anxiety and depression were higher in carers of people with an eating disorder, than the carers of people with psychosis. Higher levels of carer burden were also reported in the carers of people with an eating disorder (Zabala, Macdonald & Treasure, 2009).

Carer burden might be high for someone supporting an adult with anorexia, as the duration of the condition might have been longer, and because of the significant risks to the person's life. It might also be higher for carers of someone with anorexia because of the drive for outpatient care. This highlights the importance of making sure support for carers is made available to them, such as local support groups, forums and so forth. When providing information to carers about supporting a person with anorexia, services could also inform them about the importance of maintaining their own self-care when supporting someone with anorexia and tips and information about how to do this. The study also supports the role of carer groups as not only a place for carers to gain useful information but also as a source of support, which is important in their role.

This study found that participants were highly active in their role of trying to facilitate help seeking and offered a range of different

methods of support: informational, practical, emotional and cognitive. To the authors' knowledge, this is a novel finding. A previous study on recovery from anorexia found that individuals reported that a significant person in their life that offered consistent and unconditional support was key to their recovery, and helped them to perceive themselves as worthy and loveable (Cox & Rennoldson, 2013). However, the findings from this study illustrate that the significant other offered more than just emotional support; they offered a variety of types of support.

The subtheme unsuccessful attempts represented when participants' were unsuccessful in trying to facilitate the person to seek help. This was understood by participants as being the result of the place that the person was and not because of the methods. This finding might be understood in terms of the social support theory matching hypothesis (Cohen & Wills, 1995) that states that support is only successful when it matches the needs of the stress or problem. Therefore it could be that unsuccessful attempts were not a good match and maybe participants were offering practical support at a time when the person needed emotional support. It was not possible to know if the support offered by participants matched the need of the person with anorexia, but this might be something explored in future research, with consideration for who is judging "need" given the ego-syntonic nature of anorexia.

#### Implications for psychological theory

As discussed in the journal paper, the process that many participants reported that they went through, in trying to encourage the adult to seek help for anorexia, can be seen to map onto Kubler-Ross's (1969) stage model of grief. This has been discussed in the journal paper discussion but will be expanded on here.

Many participants in this study described how when they began to notice changes in the adult's eating and exercise behaviours, they were not concerned. Participants reported not responding to changes in the adult's eating or exercise behaviours because they did not initially think that it could be anorexia or they believed the changes in behaviour to be short term. Here participants' reactions can be seen to map on to the first stage of the grief model, "denial" (Kubler-Ross, 1969).

Once disclosure of a problem had occurred, many participants spoke about how they felt frustration and anger that the adult was unable to access treatment for anorexia, because they were told that they did not meet the service criteria. This stage can be understood as mapping onto the "anger" stage of Kubler-Ross's (1969) model. Some participants also spoke about feeling frustrated at times that the adult would not seek help, despite continuing to lose weight and it having a negative impact on their physical state.

As participants tried to encourage the adult to seek help, some reported under the theme of "self-care", that they sought private help for their own wellbeing as a result of supporting the adult. Within this theme, some participants described the loss of the person that they had known before the anorexia. Jo compared anorexia to dementia, and reflected on the differences in her daughter's cognitive ability before and after the onset of anorexia. Other participants reflected on what the adult was unable to do because of the anorexia, such as progress with education, work or continue with relationships. This theme might be explained by the "depression" stage of the grief model (Kubler-Ross, 1969), as it reflects loss experienced by participants.

Lastly, after trying different methods of support to encourage the person to seek help for anorexia, and realising that these were ineffective, many participants reported that they stepped back in

their approach. They tried to work alongside the person instead of using more direct and coercive approaches. This could be seen to fit with the stage of “acceptance” in the model of grief (Kubler-Ross, 1969). Participants were no longer fighting the anorexia but working alongside the adult.

The themes in this study illustrate that there was a clear sequential pattern to the participants’ experiences of supporting the adult to seek help. These largely map onto the stages of the grief model by Kubler-Ross (1969), which can be used to understand the psychological adaptation that participants reported.

#### Implications for clinical practice

This study used the social support theory (Cohen & Wills, 1995) to inform part of the analysis. Carers might be supported to offer each of the types of support identified by the analysis. This might be included as part of carer groups, as some participants’ in this study reported that they attended them, wanting information to know what to do to help the person.

Some participants reported that they sought their own personal support and this has implications for adult mental health services, as the participants may not have had a diagnosable mental health problem, but they reported that they found therapy beneficial. The participants in this study reported that they sought help privately for themselves, and so there might be implications for individuals who are supporting somebody with anorexia but may not have the financial resource to seek private therapy. As participants’ reported that they found self-care techniques helpful, carers of people with anorexia could be encouraged to use them earlier.

From participants’ accounts of their experiences of services, the waiting time for treatment for the person with anorexia was long, with some reporting waits of up to a year (Kate). This led some

participants to look for private help as they did not feel that they could wait for NHS treatment given the person's physical state. There are implications for early intervention: it is related to better prognosis and recovery outcomes (Treasure & Russell, 2011) and early intervention is advocated in the NICE (2004) guidelines, but in reality there can be long waits for treatment. If people do not have the financial resources to seek private help in the interim, they may not be able to access treatment as early as they need it.

Participants reported that some of the individuals with anorexia were not accepted into services if their weight was not low enough to meet the service criteria. Participants in this study seemed to step in as a result of this. Some carers might not have had any experience of anorexia. They might need support and guidance from services to be able to support individuals who are not able to access services, and to be made aware of the signs that might indicate that the person may need to access them.

### Strengths and limitations

A strength of this study is that it adds to the literature on help seeking in anorexia. To the authors' knowledge, this is the first study that explores the role of significant others in adults with anorexia. As identified in earlier sections, the majority of literature about significant others is focused on adolescents with anorexia. The perspective of significant others are important for adults, as well as adolescents, as this study found evidence of significant others working to support people to disclose problems and seek help, which is vital for the long-term prognosis of individuals with anorexia.

The study found that significant others are willing to support help seeking and problem disclosure, with the participants in this study being flexible and persistent in their approach. The findings

connect with psychological theories and existing models of support and change which might be pertinent to future research in this area.

Some of the limitations of the study will now be discussed. Firstly, the limitations and challenges with recruitment will be reported. This study was completed as part of a Doctorate in Clinical Psychology and therefore there was a time restriction for completion. The primary researcher relied on a staff member handing out information sheets to anyone that came forward and showed interest after hearing about the study at the carer groups, and people looking at the study advertisement in another service where they had chosen to display it. The link on the Beat website was amongst many other study links, so this might have reduced the chances of people taking part. With websites, it could not be controlled who accessed them and therefore, who saw the study advertisement.

The author did approach a specialist NHS eating disorder services in the East Midlands (Nottingham and Derby) at the start of the project to ask if they would be willing to support recruitment of the study. However, they seemed to have more involvement with the person with the eating disorder than carers. One service had recently asked carers linked to their service, to take part in a study. As many of them had, they were reluctant to ask them again about partaking in another study so soon. Another service explained that carers who came into contact with their service were signposted to one of the charities that the primary researcher had already made contact with about recruitment.

A further limitation was that the study was a retrospective study, so as mentioned in the journal paper, data could have been subject to hindsight bias, especially as the majority of participants spoke about events that happened over a long period of time. There could have been some inaccurate recall of details. However, qualitative research aims to explore the world as it is. Only four



participants spoke about a person with anorexia that had successfully recovered, so the study cannot comment about later stages of recovery as not many participants moved to that stage.

The majority of interviews were conducted by telephone (n=9) and the pros and cons of this method of data collection compared to face to face are discussed in the methodology. Telephone interviews have been seen as the less advantageous to face to face (Novick, 2008). However, in this study this method allowed participants from wider geographical locations to be recruited for the study. Participants were offered a choice of method for the interview; Skype, face to face and telephone and the majority chose telephone. This might suggest that they preferred a more convenient method. It was hard to comment whether there was any difference between conducting the interviews by telephone or face to face because there was only one interview to compare with. In terms of interview length, there was not a difference, and one of the telephone interviews was longer in duration, than the face to face interview.

With regards to implementing the interview schedule and development as a researcher; the researcher reflected on the first interview and saw opportunities to improve richer data. Opportunities were noted where the participant could have been probed further on their answers and this point was taken into account and improved on for future interviews.

The data was analysed by a single analyst and one of the criticisms of qualitative approaches concerns the subjectivity of the researcher (Madill, Jordan & Shirley, 2000). However, a critical realist epistemology position recognises that the way information is understood is dependent to some degree on the person's own beliefs and expectations (Bunge, 1993) and it is recognised that there will be some integral bias in the production of knowledge (Madill et al. 2000). Even though the primary researcher acknowledged that they

will inherently have some influence over the way data is collected and analysed, they endeavoured to produce a detailed methodology and present the study findings with transparency.

As noted in the methodology section, six interviews were transcribed by a professional transcriber, and ideally all interviews would be transcribed by the researcher as a first step in helping them to gain familiarity with the data (Braun & Clarke, 2006). However, because of the time limits to complete the study, it was felt that it would be best to use the extra time to read through the transcripts to gain familiarity with the data and start thinking about initial codes.

### Future research

There is a substantial amount of existing literature on drop out from treatment in anorexia, but this study suggests that future research might explore staying in help. A future study might explore what factors contributed to someone staying in help.

This study only captured the perspective of the significant other about their experience of trying to encourage the person with anorexia to seek treatment. It was not known what the person with anorexia made of this support, and whether they would have even perceived the participants efforts as supportive. A future study might investigate the perspective of people with anorexia, about how they experience significant others in trying to encourage them to seek help and what, if any, approaches they found helpful and unhelpful.

There are also some strengths and limitations around the single perspective of this study. Only significant others were interviewed, which was a strength because the study aimed to understand significant others within their own understanding. However, it is also a weakness, because it is unknown how this support was received by the person with anorexia, and it was not possible to triangulate whether the support was actually as described.

Many participants in this study reported that they stepped back in their approach to support the person to seek help. Stepping back was a key finding from this study and so future research might explore this further. A future study might explore the person with anorexia's views on stepping back support; how it was experienced and whether they found it helpful or not. Future research might explore in more detail what helped people to step back, and as only a few participants in this study commented on its effectiveness. This could be explored in a future study. If it is found that stepping back is effective, then services might be able to support carers to take this approach earlier through the information that they provide about supporting someone with anorexia. Although this approach of stepping back seems to be advocated in carer groups it might be helpful to provide this information in other sources to increase chances of carers accessing it, such as leaflets available in services or GP surgeries, because for some participants in this study it took a long time for them to find out about this approach.

Lastly, there was some variation in the category of "significant other" that took part, but the majority were mothers, and there was less representation of friends and partners and none for siblings. Although qualitative research does not aim to produce generalisable findings, the sample was quite homogenous. In order to see if there were any similarities or differences in experiences it would have been useful to have a more diverse sample and hear more friends, partners and different family members' voices. Furthermore, all participants spoke about a woman with anorexia and it would have been interesting to have also heard about supporting a male with anorexia to seek help. This might be a future research study.

### **Critical Reflection**

In this section I will critically reflect on my experience of the research process, focusing specifically on the process of recruitment,

the method of data collection and data analysis. Part of this reflection will include reference to material from my research reflective diary.

### Reflections on recruitment

Regarding recruitment when I started to hear from people about taking part, a few individuals' contacted me at about the same time. I felt really excited that I was getting suitable people coming forward and thought (somewhat naively) that my target to recruit up to 15 participants would be easily achieved. However, following this I experienced a period where no one contacted me about taking part and I began to worry that I would not have enough participants. Discussing this in supervision helped me to normalise my worries and understand that recruitment is a difficult process. I then made a decision to ask the facilitator of a carer group to resend out the email about my study to capture anyone else that might have wanted to take part and this led to some more suitable participants being recruited. Shortly after this, the recruitment officer from Beat inquired about how recruitment was going and sent out a tweet about the project to try and boost uptake. I had another suitable participant come forward as a result of this. Despite advertising the study in different places, all but one of my sample were recruited from the same source. Although I had an adequate sample size for thematic analysis, I wondered whether the fact that the study focused specifically on adults, and on anorexia, reduced the amount of people who met the criteria to take part. I noticed when I attended the carers group to talk about my study, that many of the members commented that they only had experience of supporting an adolescent, or someone with a different eating disorder such as bulimia.

I have thought about what might have been the motivations of those who decided to take part. I wondered whether because the majority of participants had reported that trying to support the

person with anorexia to seek help had been a difficult experience, if it was helpful to have their experiences heard. I wondered whether maybe they took part in the study to have their actions validated. A couple of participants said that they found the interview cathartic, Helen commented that it was good to, "get it off your chest". Furthermore, regarding motivation to partake, the majority of participants were recruited from a carer group where they might have been experienced in sharing their story with others hence more willing than others to come forward to take part.

### Reflections on the interviews

Most of the interviews were conducted by telephone. It was a convenient method that allowed me to recruit people from a wider geographical location. When I was designing my study and decided to include this as an option, I imagined that most people would have chosen face to face and was surprised that the majority of people chose the telephone. Although I have conducted qualitative research previously, and used semi-structured interviews, they have only ever been conducted face to face.

In my previous job in IAPT (Improving Access for Psychological Therapies) a lot of the assessments and treatments that I did were conducted on the telephone initially. This gave me some confidence in conducting my research interviews over the telephone. I remembered the importance of using verbal communication skills on the telephone to help to build rapport. In my first research interview I used a lot of verbal prompts throughout (e.g. "uh-ummm"), empathy and summarising. When I listened back to this interview, the use of verbal prompts made the participant aware that I was listening to them and encouraged them to continue, and I was pleased that for my first interview I felt I had a lot of good material. In terms of my style, with my frequent empathising and summarising, at times I felt that I had moved into more of a clinician role than a researcher.

Sometimes where I had responded with verbal prompts, I noted moments when I could have further prompted the participant to say more. I wondered if because of my previous therapeutic telephone work I had automatically used the skills on the telephone that I was taught for that role, especially as I wanted to make the participant feel at ease on the telephone. Feeling that I had slipped into the Clinician role could also have been the influence of my current role as a trainee Clinical Psychologist. Being aware of this from my first interview helped me not to repeat it in future interviews and focus on using my researcher skills.

### Reflection on the analysis

#### *Reflective Journal Excerpt*

*I was feeling really overwhelmed by my data at times when trying to refine the themes. I have had a few days not looking at my potential themes and have returned with fresh eyes and I can now see where some themes could be combined. For example, there is a theme that I have labelled as "learning through experience" and includes codes such as "controlling not helpful" and "modifies own behaviour". This theme could come under the broader theme of "stepping back".*

This extract was written when I was at the stage of analysis of refining my themes. At times I felt very overwhelmed by my data and would spend long periods of time looking at it and trying to refine the themes. I imagine this is a normal feeling in qualitative research. Allowing myself time away whilst focusing on other aspects of my project helped me to come back to the data with a clearer perspective and improved my ability to see the overall connectedness of the themes.

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## **Appendices**

## **Appendix I: Example of coding**

Initial codes (seen on transcript) were analysed to categories. Below are the initial codes included in the category labelled "First Response"

### **Codes in first response category:**

Parents in denial 6:13  
Reacts to suspicion fast 3:2  
Did not comment about weight loss 4:2  
Didn't make an issue about eating behaviour 4:2  
Denial that daughter had an eating disorder 4:2  
Observing and waiting 4:3  
Denial 4:3  
Got therapist in place quickly 4:7  
Family panicked 4:11  
Family anxious 4:11  
Looked up information on the internet 1:10  
Husband voiced concerns to wife 5:2  
Researched health problems 1:15  
Husband encouraged wife not to react 5:2  
Mum verbally expressed concerns to daughter 2:5  
Weighed daughter 2:6  
Hopeful would recover fast 2:23  
Panic led to seeking help quick 2:29  
Suggested a visit to GP 7:2  
Felt daughter was supported at University 8:5  
Reluctant for daughter to leave Uni 8:5  
Confided in a friend 10:5  
Uncertain about what to do 10:6  
Sought confirmation of suspicions 10:22  
Panic 6:9  
Husband encouraged to stay calm 6:9  
Want to force feed them 6:10  
Bought a ton of food 6:10  
Weighed her 6:10  
Friends expressed concerns 2:10  
GP first port of call 3:2  
Suggested speaking to GP 5:3  
Went to GP 2:4  
Daughter urged parents to help 8:5  
GP commented about weight 6:11  
Friend disclosed eating problem 10:7  
Friends expressed concern to parents 8:3  
Mum suggested exercise 2:3  
Believed her when she denied a problem 6:12

An example of the coding procedure of how the theme First Response was formed.

**Category 'First Response' initially included the following codes:**

**First response**

Parents in denial 6:13  
Reacts to suspicion fast 3:2  
Did not comment about weight loss 4:2  
Didn't make an issue about eating behaviour 4:2  
Denial that daughter had an eating disorder 4:2  
Observing and waiting 4:3  
Denial 4:3  
Got therapist in place quickly 4:7  
Family panicked 4:11  
Family anxious 4:11  
Looked up information on the internet 1:10  
Husband voiced concerns to wife 5:2  
Researched health problems 1:15  
Husband encouraged wife not to react 5:2  
Mum verbally expressed concerns to daughter 2:5  
Weighed daughter 2:6  
Hopeful would recover fast 2:23  
Panic led to seeking help quick 2:29  
Suggested a visit to GP 7:2  
Felt daughter was supported at University 8:5  
Reluctant for daughter to leave Uni 8:5  
Confided in a friend 10:5  
Uncertain about what to do 10:6  
Sought confirmation of suspicions 10:22  
Panic 6:9  
Husband encouraged to stay calm 6:9  
Want to force feed them 6:10  
Bought a ton of food 6:10  
Weighed her 6:10  
Friends expressed concerns 2:10  
Went to GP to talk over concern 2:4  
Daughter urged parents to help sister 8:5  
Friends expressed concern to parents 8:3  
Believed her when she denied a problem 6:12

The following three categories and their codes were later amalgamated to become part of "First response" which became a superordinate theme.

### **Initial weight loss seen as positive**

Encouraged weight loss 3:2  
Positive reaction to weight loss 4:2  
Praised weight loss 2:3  
Praised weight loss 7:5  
Weight loss seen as positive 6:7

### **Participant took the lead**

Made an appointment at GP 3:2  
Arranged for private therapist 4:4  
Arranged appointment with long standing GP 8:6  
Took control in booking GP appointment 1:16

### **Anorexia was unexpected**

Happened quickly 3:2  
Anorexia unexpected 4:2  
Didn't fit anorexia stereotype 4:2  
Unexpected 4:2  
Anorexia the last thing on my mind 5:2  
AN sudden 5:17  
Anorexia came on suddenly 5:2  
Never going to happen to your child 2:2  
Shock at weight loss 2:5  
Daughter low risk for AN 7:28  
Low risk for AN 7:29  
Mild surprise 8:5  
Completely missed the anorexia 8:11  
Shock at appearance 5:10  
Shock 6:8

## Appendix J: 'Worked' anonymised Transcript

Interview Data	Initial codes
<p>I: Have you any questions before we start?</p> <p>P: I don't think so, but can I ask mid-way through if something's not clear?</p> <p>I: Yes, definitely. Ok we'll start with the first question. Can you tell me about your relationship with the person you'll be talking about? If you want to use their name, when I write up the interview, I will change it to keep it anonymous.</p> <p>P: Yes ok, that's fine. She's called Claire<sup>10</sup> and I'm her mum. We've always had a really good rel- do you mean how is the quality of our relationship?</p> <p>I: Well I guess I was asking people about how they know the person, and so you're her mum. Does she live at home with you?</p> <p>P: She does. Yes, Yes.</p> <p>I: Ok, what did you know about anorexia, before Claire?</p> <p>P: Very little really. I guess I just thought people were a bit self-indulgent and erm, looking from the outside you don't really have any understanding of why they don't sort themselves out [laughs] and then when you're faced with it your looking ins changes quite a lot. You see so, it's not really a lot.</p> <p>I: Ok. What were the first signs that made you think that Claire needed to seek support?</p> <p>P: Erm, avoidance of food at home and suddenly go- I mean Claire was a very talented rower, so had been eating 4000 calories a day kind of stuff and then erm, then suddenly "no, I don't fancy that for dinner I think I'll just have an egg on toast. It started off becoming two eggs on toast, then it became one egg on toast, you know avoidance of food. She's always been erm, because, I guess, she's</p>	<p>New little about AN Did not understand behaviours Experience changes understanding</p> <p>Avoiding food first sign</p> <p>Changes to diet</p> <p>Gradually reduced food</p>

<sup>10</sup> All names have been changed for confidentiality

<p>five foot two, but never fat, she never had an ounce of fat on her but because she was rowing she was very muscly. And actually, it didn't show physically, for a while I would say. So it wasn't that she suddenly – but I did notice that she had lost some way, but in the stupid way that you do, I said, “oh god, you look fantastic in those new trousers.”</p> <p>I: Yeah</p> <p>P: And not realising and it was more the avoidance of food.</p> <p>I: Mmm. Was that just at home? Did you notice anywhere else?</p> <p>P: Erm, probably not wanting to go out to restaurants, that kind of thing. But to be honest really, it was the avoidance of food.</p> <p>I: Mmm, so when you noticed her asking for smaller portions of food or avoiding food, what did you do?</p> <p>P: Well I guess it all happened very quickly. I believe she became ill around the Christmas, but it was round about her birthday, the beginning of March that I really noticed. And I thought about it for a couple of days and then I just said one evening I just said, “Claire, you know, what is wrong?” You know, basically saying “Do you have an eating disorder?” and she, at that stage, she just burst into tears and said, “Yes.” And I said “right, we’ll made a doctor’s appointment, we need to get looking into this” and she was very amenable and I said – at our practice our GP, she’s a very good doctor but quite curse. And I said “Lets make an appointment to see the female GP” and we couldn’t get an appointment to see her for about 5 days and so I made the appointment and went to see her. And, she was terrible [laughs]</p> <p>I: Ahhh</p> <p>P: And so I went into her office, both of us, sobbing, saying Claire had an eating disorder and she said, “Well does it hurt to swallow?”</p> <p>I: Oh right.</p>	<p>Gradually lost weight</p> <p>Positive reaction to weight loss</p> <p>Stopped wanting to eat out</p> <p>Avoidance of food</p> <p>Happened very quickly</p> <p>Confrontation</p> <p>Confession</p> <p>GP first port of call</p> <p>Taking the lead</p> <p>Participant made GP appointment</p> <p>GP terrible</p> <p>Inappropriate response from GP</p>
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<p>who was in the same year as Claire, had had anorexia and coincidentally we dropped the girls off at the same time. And as soon as the girls were out of sight and – had put down her car window I said “help” and she was fantastic. But erm, she told me about a private clinic she had been involved with in London and I managed to get Claire an appointment with the psychiatrist there, literally the next day.</p> <p>I: wow</p> <p>P: And she saw Claire and said, “Yes I think she is on the verge on an eating disorder, come back and see me in a week or two.” Then, the next – erm, trying to think of the process. So we made an appointment to see her in just over a weeks time, in 10 days time or something and, but in the meantime, Claire, I think she is unusual cause she cuts down very, very drastically, so I phoned the – I was looking into it and there was so little information available, really so little information and I found out about CAMHS, so I phoned the local CAMHS office.</p> <p>I: Was this finding out on the internet? Were you looking on the internet?</p> <p>P: Yeah I think so and also asking this friend whose daughter had been through it and was going through it at the same time and erm, and I phoned CAMHS on the Monday and I told them, just the receptionist on the phone, what she was eating, and she said “for goodness sake, stop pissing about, take her to A&amp;E now.” So I took her that afternoon to – which is our nearest A&amp;E in -. So we took her there and I had to plea to get seen, so, and eventually they called the duty psychiatrist over and he said “Yes she has a serious problem, I’ll make an urgent referral to CAMHS” and so the next day I was crossing my fingers waiting to hear something, phoned our local CAMHS and said have you had the referral and they said</p>	<p>Sought advice from another on what to do</p> <p>Got appointment immediately</p> <p>Told was on the verge of having an ED</p> <p>Cut food down drastically</p> <p>Little information available</p> <p>Asked others who had same experience for advice</p> <p>CAMHS receptionist advised to take daughter straight to A&amp;E</p> <p>Psychiatrist confirmed problem serious</p> <p>Chasing up referral</p>
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<p>“No” and I phoned – basically I sussed out that the stupid psychiatrist had sent the referral to the wrong County.</p> <p>I: Oh.</p> <p>P: And I went back to see our own GP, the one I didn’t see the first time cause he was a bit brusque and he was lovely. And he said to me, “Look, you’ve got private medical cover, go”. And Claire was doing a revision course in London and I wasn’t letting her travel on the train cause I thought she’d collapse. Wouldn’t let her travel on her own, so I was going in with her. And the next morning I went in with her and I was lost, I didn’t know what to do. Sorry, I’m getting very emotional about this [crying].</p> <p>I: Ah, I can imagine. It’s alright, just take your time.</p> <p>P: Yeah. I phoned the psychiatrist office again and said this is desperate, and it wasn’t that her weight was so low, it was probably borderline anorexic rate.</p> <p>I: Mmm.</p> <p>P: It was that she’d stopped eating and drinking.</p> <p>M: Mmm.</p> <p>P: And they said to bring her that afternoon, so I took her that afternoon to -. Excuse me.</p> <p>I: That’s alright.</p> <p>P: And the psychiatrist said to her “Claire I want you to go to the – and just stay overnight so they can run some blood tests.” And so she went to stay overnight and the results, because she hadn’t eaten, we so bad, that she actually stayed in there for about six weeks.</p> <p>I: Ok</p> <p>P: And I don’t know if you’re very – but in the meantime I’d been in contact with CAMHS saying “What’s going on” and they said her case will be reviewed at the next meeting, which will be in a weeks time and the woman on the phone said she is “One of sixty cases,</p>	<p>Referral sent to wrong County</p> <p>Advised to seek private help Fear around physical health</p> <p>Lost at what to do</p> <p>Lost – called psychiatrist Expressed worry to psychiatrist</p> <p>Stopped eating and drinking</p> <p>Psychiatrist advised overnight stay and blood tests</p> <p>Ended up staying in longer</p> <p>Participant chased up referral</p>
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<p>six zero cases, that we are reviewing that day.” And I thought, “Well we can’t wa-</p> <p>I: Wait. You hadn’t been seen by CAMHS at this point, you were still waiting to be seen?</p> <p>P: Yes absolutely. So Claire did six weeks in the private thing, their treatment was very much tailored to what people will pay, and then when you pay quite a lot [laughs] and she came home. And through all of this she was still 17. So she literally had just turned 17 when she was diagnosed. And so, she didn’t do her AS Levels that year and so she was going to repeat the year, she was very happy to repeat the year. Trouble is, her sister was then in the same year because there’s not a big age difference between them. So she went back to school doing her AS levels alongside her sister and she was fine. Up until her 18<sup>th</sup> birthday, she seemed to be having this <i>miraculous</i> recovery. You know, she had gained weight, she was about up to 61kgs, which is about a BMI of about nineteen and a half for her. You know very - I mean at her 18<sup>th</sup> birthday party she seemed to be on top of the world, she didn’t want to go out for dinner [laughs] which I should have seen as a sign.</p> <p>I: Mmm, but physically she was looking better and her mood seemed improved so –</p> <p>P: Absolutely, really good, and then she turns 18 and it was like she had been waiting.</p> <p>I: Ah right</p> <p>P: And the stress of her AS exams coming up again, and she’d lost a lot of her confidence. She’s a bright girl, she’s at Grammer School. You know, but she completely lost her academic confidence. And so there was a big stress about the exams, and I know she went back in – for a bit, which is private place, I can’t remember the sequence of events. But, she managed to do her AS <i>exams</i>, she didn’t do brilliantly in them, but she did them. But then her weight</p>	<p>Can’t wait for CAMHS</p> <p>Did not do A Levels</p> <p>Repeated year with sister. Recovering well up until 18<sup>th</sup> birthday Had gained weight</p> <p>Missed signs</p> <p>Turned 18 everything changed Change planned</p> <p>Exam stress Low confidence</p> <p>Did AS exams</p> <p>Weight began to drop</p>
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<p>was dropping and we kind of - and through this she'd been doing some day patient stuff as well with the –which we were funding at the stage. And then I'm Australian and we have very close ties to our family in Australia, we had booked, when she was doing so well around her 18<sup>th</sup> birthday, we had booked for us to go to Australia over the summer, but then she started losing weight again and we were in with the – trying to hold it out to her like a carrot you know, "If you weigh enough then we can take you to Australia".</p> <p>I: Yeah, like an incentive really.</p> <p>P: Yes very much an incentive, but it didn't work that way. And last year was terrible because I had Michelle doing her AS levels as well.</p> <p>I: Mmm</p> <p>P And things were – Claire was terrible, she kind of kept me on side, but she was so sell to her father and so sell to her sister</p> <p>I: Mmm</p> <p>P: And so anyway, it was coming up to the time we were going to Australia and coming up to the time she'd been back in the – as soon as her AS levels were finished she went straight back into the – again on Bupa cause you get like six weeks a year or something, and she, erm, she was just going downhill, fast, you know they force fed her like a goose really, to get her weight up, to go to Australia and she did reach the weight, but psychologically she was in no position.</p> <p>I: Mmm</p> <p>P: It became clear to us that what she was doing was eating to get on that plane. And that as soon as she got on the plane,</p> <p>I: That was it</p> <p>P: Yeah, there was no way – and you know, my was that we would get her to Australia and we would call a hospital in Sydney and say "help". So in the end we took a very difficult decision that Michelle</p>	<p>Doing well booked a holiday</p> <p>Started to lose weight again</p> <p>Used holiday as an incentive</p> <p>Holiday as incentive not successful</p> <p>Went downhill fast Force fed</p> <p>Reached the weight Psychology no position to go on holiday.</p> <p>Eating for purpose</p> <p>Feared relapse on holiday.</p>
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<p>and I would go to Australia, cause I was cracking up, Michelle was you know, cracking up and David would stay here and we had at that stage got an appointment with adult services for her to be, what's the word, assessed, so this was the end of July last year. Oh and she went <i>missing</i> over the weekend, that Michelle and I went to Australia and she was devastated. And we thought, well maybe this will be the <i>thing</i>, she always use to say "I haven't reached rock bottom" I don't know if that's (inaudible 1750) or not, but she use to say "I haven't reached rock bottom". And so they put her into – do you know it? – which is the specialist eating disorder service for our area.</p> <p>I: Yeah.</p> <p>P: And the thing about Claire is, whenever she is in treatment. She will just do exactly as they say and be very amenable, and you know, erm, and they will think "she is so compliant, we can trust her to go home". And so we came back from Australia and that pretty much coincided with her coming out of – house. And it was all very sunny and she was going to go off and do her A2s and [pause] then she got lumbered with extra responsibility at school which was a huge mistake and we all should have seen it coming and between that and the A2's and lack of confidence and everything else she went downhill, and she was only back at school for I don't know, maybe a month.</p> <p>I: Mmm</p> <p>P: And she went downhill very badly, and again she has this thing which they say is very unusual, but she literally stops drinking as well.</p> <p>I: Mmm</p> <p>P: And so she collapsed at home and we called an ambulance, and I was taking Michelle to her Saturday job and she collapsed and David called an ambulance and they came and her glucose level</p>	<p>Family needed a break Cracking up</p> <p>Devastated missed out on holiday</p> <p>Hadn't reached rock bottom</p> <p>Compliant when sought treatment Compliant with treatment to get home</p> <p>Stress a setback</p> <p>Lack of confidence Went downhill</p> <p>Went downhill quickly Stopped drinking</p> <p>Collapsed at home low glucose</p>
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<p>was two when it should be, I don't know very much higher. And so, they put her into the ambulance and they couldn't get a drip into her because she was so dried up.</p> <p>I: Ahh</p> <p>P: And so she got through, they took her to this – hospital, the staff were fantastic. And they put her on a drip, which she, <i>tolerated</i>, but even though she was on a drip in a life threatening situation, she still wouldn't even take a sip of water.</p> <p>I: Mmm right. If you asked her was she able to say why? Or what it was about the water?</p> <p>P: It was just that once she'd cut stuff out, she couldn't put it back.</p> <p>I: It was all or nothing?</p> <p>P: Yeah and every time she cut something out, she then had to cut something else out, so it was like a runaway train going downhill really. But she did say if you get me into – house I will eat. She didn't trust anyone at the hospital, not to give her, something, extra. No and she said "if you can get me into – house I will do what they say there," and she is aware of re-feeding syndrome and all of that kind of stuff. So she went back into – house, and she was there for two months and in the end they had a meeting and said "you know, look Claire is not intending to get better, she's <i>not</i> engaging with any of the programmes" which actually is very interesting because we had been saying, "It's really funny that they don't have any programmes on at – house or therapy." And at this meeting there was about 15 people sitting around and us and Claire and you know, and I said "it's really funny you don't have anything therapy wise" and they said "we do, but Claire wont engage with it." And I went "Oh ok, that explains a lot" [laughs].</p> <p>I: And did you have the impression that when she asked to go there she was being very compliant and she was doing, getting, during –</p>	<p>Too dehydrated to insert drip</p> <p>Tolerated drip Refused water in life threatening situation</p> <p>Strict rules around food</p> <p>Cutting out became obsessive</p> <p>No trust in staff at hospital</p> <p>Not engaging in treatment</p> <p>Parents unaware was not engaging in treatment</p>
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<p>P: Yes we did and we thought she was being fully involved in everything they had, but they just didn't have anything. And of course, because she is over 18 they don't tell you anything.</p> <p>I: Mmm</p> <p>P: And you know, unless you phrase a question in the right way, for example, when she had come out, in the August to go back to school, she had been meant to go every week to see the psychologist and she came back and said "they only want to see me every couple of weeks,"</p> <p>I: Ahh</p> <p>P: And I thought, well that's really odd.</p> <p>I: Mmm</p> <p>P: And obviously I phoned them, when she started to really go downhill again and said, you know, "She's not being <i>seen</i> enough" and they said "Well Mrs – I can't tell you anything but what I will say is that it wouldn't be our practice to see anyone so infrequently". So she had to (inaudible) them that she wasn't going to go and so</p> <p>I: But had said, "they just want to see me that often"</p> <p>P: Yeah and (inaudible) you only know what she's telling you.</p> <p>I: Mmm, mmm.</p> <p>P: And I suppose if she is going some weeks it might seem quite plausible because she had been going.</p> <p>I: Absolutely. So she went back and they said they were going to discharge her because she wasn't – because they couldn't help her, because she wouldn't allow them to help her and there were other girls that needed the help. And you know, I understand that, as hard as it was [laughs] and so, but in the meantime I had gone on a, carers day, that they run from – house and one of the speakers was one of the nurses at – house. And he's, a lovely man, he has <i>quite</i> a pronounced speech impediment, and Claire had just ridden</p>	<p>Confidentiality a barrier to information</p> <p>Dishonest to parents</p> <p>Rang services when went downhill Blamed services</p> <p>Discharged from services for not engaging.</p> <p>Provided information</p>
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<p>him off. but I said to her “Look, you should talk to Ryan, he gave the <i>best</i> talk” so I said to her on the day,” his was the <i>best</i> by far” and she did – she was in there for sort of three weeks after they said they were planning to discharge her, and he did a one to one with her every day for those three weeks. And, I think she just finally kind of listened a bit.</p> <p>I: Mmm</p> <p>P: Anyway, she came home and said she’d maintain the weight that she was, which I’m guessing was a BMI of about 16. So you know way below healthy – it may have even been 15 something, I don’t know. And I, you know, to save my own sanity in a way and to make it work, we kind of agreed that, I would help her, sit with her, but I wouldn’t comment on her portions, or try and make it more than she was willing to eat and she’d been seen – we did agree that she would see the psychologist <i>every</i> week.</p> <p>I: Mmm</p> <p>P: And because I was worried about her driving at that weight, I said I wouldn’t trust her to drive, it was about a 40 minute drive so you know, you can’t drive that far, “I don’t feel <i>safe</i> with you driving so I will take you”, which was also my way of making sure she was going [laughs]</p> <p>I: Yeah, yeah.</p> <p>P: I mean, you know, touch a load of wood, at about Christmas time we had – it’s close, we go to – for the meetings, there’s no family therapist there so the head of – house, had agreed to do a couple of family therapy sessions with us, and Claire had sort of been making <i>murmurings</i> about, trying to you know – that she was missing out on life, and she wanted to, you know, maybe do something about that. And also, when she was admitted to hospital and put on a drip, it was like it was happening to somebody else, you know, she was just totally not involved in it.</p>	<p>Engaged-listened a bit</p> <p>Maintained weight at home</p> <p>Agreement around meals</p> <p>Agreement around treatment</p> <p>Worries around low weight Framing Took her to appointments</p> <p>Family had family therapy</p> <p>Daughter murmurings about missing out in life</p> <p>Passive in treatment Not engaged in treatment</p>
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<p>I: Mmm quite passive.</p> <p>P: Absolutely, but she said since then, when she came out of that, she realised how dangerous that was.</p> <p>I: Mmm, do you think it was that one incident that made her probably realise, the seriousness of it</p> <p>P: I think so, yes I do think so, and when she was a bit more well she could look back on it, whereas at the time she wasn't capable of looking at it at all, and so touch wood, at the minute, and I know this could change [laughs] and I'm touching a lot of wood. She's <i>trying</i> to get better.</p> <p>I: Mmm mmm.</p> <p>P: And it's very hard for her, but she's started to – like today, the reason I could talk to you today is because Friday she is doing an all-day life drawing class.</p> <p>I: yeah</p> <p>P: She loves to draw, and, she's quite good at and so she's do- so it's not – she's, <i>just</i> started talking about maybe getting a part time job somewhere, I mean she's not finished school and she's not going to finish school, and that's got an impact on her future, but, but at the minute we're not trying to think that far ahead you know.</p> <p>I: Taking little steps at a time</p> <p>P: Yes</p> <p>I: When you noticed she hadn't been to an appointment, or had said that there weren't any therapy sessions on. What did you do about that, did you approach her or were there other ways, you mentioned you would go with her to an appointment, s you could see that she was going.</p> <p>P: Yep</p> <p>I: Did you ever bring it up with her?</p>	<p>Realised dangers of behaviour</p> <p>Daughter could reflect in hindsight No insight at time</p> <p>Functioning improved One step at a time</p>
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<p>P: Yeah, when it came out in that meeting that she had been avoiding all the therapy, you know we went back in to – house to have a chat with her after the meeting and that’s when I said, “you should talk to Ryan, I mean I know he’s a good chap” and then they arranged a family therapy meeting for us at – house, and I thought Claire was going to just kick off so bad because she was vitriolic about the family therapist she said she was a complete waste of space and so I didn’t bring Michelle to the meeting, cause I thought it was going to be a terrible, terrible meeting, and we went in there and this family therapist in an hour and a half was just phenomenal and Claire was listening and taking part and contributing, but she had been <i>anti</i> going into that meeting, so it’s very interesting I think. I mean when she went into hospital in October, David and I were like “<i>Please</i> section her, you <i>have</i> to do something” and they were like “No, no, no, because she’s gone in we can’t section her, but you know that’s something we will look at in the future if we need too.” And you know at this stage she hasn’t had to be sectioned but I think it has been pretty close, a couple of times.</p> <p>I: Mmm and do you think in your approach to supporting her, did it change at any time did you have to try different ways?</p> <p>P: Yeah, absolutely because I, when she came out of – house, no not – house, the - , the private place, it was just feed her up, feed her up, feed her up, you know, there approach is very much, if you can get her to this weight, then her brain will start to work better. And then I went to a support group in London, just one or two times a day there, and the woman there said, “you know, they can’t get better until you, let them take responsibility for themselves”, and because I was so last year I started seeing a therapist in London myself.</p> <p>I: Mmm</p>	<p>Talking Communication</p> <p>Information persuasion</p> <p>Vitriolic about family therapist</p> <p>Mother apprehensive about involving other daughter</p> <p>Daughter engaged well in family therapy.</p> <p>Desperate for daughter to get help</p> <p>Treatment focus on weight gain.</p> <p>Need to take responsibility</p> <p>Participant sought own therapy</p>
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<p>P: And she, has worked her whole career in eating disorders, and she said, “She’s 18, she has to take responsibility for herself” so the kind of stepping back, erm, and you know, allowing Claire to fail, and she did fail spectacularly, you know, she absolutely did. But, we let it happen, because it was almost like she had too.</p> <p>I: Mmm</p> <p>P: And I’m not saying she won’t fail again, but one of the things one of the therapists in London was saying was “she can’t get better until she lives in an atmosphere that allows her to get better”, and I mean I didn’t- we had a happy family, we were generally quite close, the things that caused Claire’s illness was partly the rowing and partly some other factors that were external to us. And I’m not saying that maybe we didn’t have too high expectations and this that and the other, but generally we had a happy family, so I’m not <i>entirely</i> sure what she meant by that, but the stepping back and allowing her to take responsibility for herself, [pause] has been good. And she’s really opened us now, I mean she tells us stuff, she’ll tell me stuff and then tell the rest of us. Or something major that came out a couple of weeks ago, she actually told Michelle (sister) first. And that was, that made me very happy because the sibling relationship with anorexia is just so difficult.</p> <p>I: Mmm, yeah. I guess they are similar ages as well aren’t they.</p> <p>P: yeah there’s only 16 months between them so, yeah and us trying to keep Michelle safe, because I know there’s a a huge increase risk of her, and in fact she saw a counsellor, I means she went through it, not a very <i>long</i> stage, but she went through it, where she was self-harming last year, which I think was due to the pressure of what had been going. I don’t know if you’ve ever lived with (inaudible) but it is hell on earth.</p> <p>I: Mmm</p> <p>P: It really is</p>	<p>Age 18 has to take responsibility</p> <p>Realisation daughter has to make own choice</p> <p>Anorexia triggers</p> <p>Stepping back Daughter taking responsibility Communication Daughter opened up</p> <p>AN affects relationships</p> <p>Hard for carers Affects family Hell on earth</p>
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<p>I: Yeah it had an impact on her as well.</p> <p>P: Yes it did</p> <p>I: What do you think the biggest differences were in trying to get her to seek help over 18 and under 18? What were the biggest differences?</p> <p>P: Oh just a lack of knowledge, for us.</p> <p>I: Mmm</p> <p>P: Not being able to be involved and literally going from one day being able to know her weight, and what she was doing and wasn't doing, and every single thing about her. I know she was over 16, but she'd kind of gone along with all that. To her, she'd just – an utter [pause] you know we were still, her <i>carers</i>, and we - carers with a big c because when someone's that ill, you are there carer. That's like having no access to knowledge at all, and you know as much as I think people try and help you, they're bound by the law.</p> <p>I: Yeah, yeah. Was she different? Cause you said services were different because their confidentiality rules change when someone over – when they turn into an adult. Was she very different? Did you notice a big difference in her?</p> <p>P: Yes she became much more, erm "I know my rights, and you're not in them" sort of thing, you know, that's not like Claire. Erm, but, erm, I mean probably its erm makes her more likely to get better, but she is the sort of person who will <i>try</i> to do the right thing.</p> <p>I: Yeah</p> <p>P: And you know at the (inaudible) so abusive. But I have to say, me, going to Australia and leaving her with David, terribly hard, because their relationship at this stage was absolutely on the rocks, and she <i>hated</i> him, and then it just allowed them to develop their relationship, which is now, brilliant.</p> <p>I: Yeah, gave them some time.</p>	<p>Feeling excluded Not knowing</p> <p>Excluded family Bound by the law</p> <p>Excluded family</p> <p>Acting out of character</p> <p>So abusive Effects on relationship</p> <p>Talking More open</p>
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<p>P: Yes so erm, see. [laughs] yes, it did definitely change. But now, I guess now, she's being more <i>adult</i> about it and she'll talk about – I mean she still has terrible days, don't get me wrong, where its all, and it comes down like a , sort, of grey curtain that comes down, and you can see it, and you're just powerless to, do anything about it. But erm, there not, I mean she had one earlier this week because her sister Michelle ate some grapes. And Claire hates fruit and really hates grapes [laughs] and she just went into one completely because Michelle ate some grapes.</p> <p>I: Yeah</p> <p>P: And you know I said to Michelle “You want to eat grapes, you eat grapes” and she's going to have to learn to live with it.</p> <p>I: Yeah.</p> <p>P: And that's the – whereas before it would have been much more [whispers] “Ok Michelle, can you just take the grapes out of the room” and now its actually “Claire, sorry [pause] you have to deal with that”</p> <p>I: Mmm have to adapt. Looking back over the years what has gone well in your attempt to get her to seek support. Because she has sort support hasn't she.</p> <p>P: She has. Erm, I think, she's never, absolutely said no to it, but she's kind of – I would say that's generally gone well. What I has gone badly, is that hasn't made her eat anything [laughs]</p> <p>I: Yeah</p> <p>P: At the time when she hasn't want to be seen help hasn't – I mean she's always compliant when she's in, bit not necessarily when she is out. I mean she is at the moment, very, very good.</p> <p>I: Mmm and has she always been compliant, if you've suggested other places for her to go, she's always gone along with that?</p> <p>P: Yes, I would say, and when Michelle and I went to Australia it was very touch and go if she would go to that meeting with David.</p>	<p>Being more adult Bad days</p> <p>Struggles around others eating.</p> <p>Not altering behaviours</p> <p>Change in families reaction Family not changing their behaviours</p> <p>Agreement to treatment</p> <p>Not increased food</p> <p>Compliant with treatment when in not when out</p>
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<p>That assessment meeting, very touch and go, but actually they had – we went on the Friday and she [pause] took off for her friend's house and luckily her friends have been brilliant. And David, had to sort of stay there. Then on the Sunday, she still hadn't eaten or drank anything and was telling everyone that you know "Oh I had a drink when I was out" you know obviously, making – and nobody was believing her at that stage, but erm, telling stories and they called David and took her to – where they put her on a drip. Erm, because she was so dehydrated and I think that was- and then her and David had a cuddle and, that was kind of a starter and then they - she was more – I think if that hadn't happened she wouldn't have gone to the meeting with him on the Tuesday, so I guess through weakness [laugh[s] she's been compliant.</p> <p>I: yeah, yeah. And I guess when things have got out of her control she's gone along with things. Has she always been quite responsive if you've suggested different therapies for her to go to?</p> <p>P: No. I mean I went to a talk on cognitive hypnotherapy and the talk was given by a girl who had recovered and erm, and you know it as quite interesting and erm, so I suggested it to Claire and very much, "No, that's not for me" and also various books and stuff I had come across and tried to give her to read, erm and its been – do you know about mindfulness?</p> <p>I: Yep yes.</p> <p>P: That kind of stuff, and it's been- in fact, I haven't approached her on the mindfulness for a bit, but there's a book called, "lighter than my shadow" have you come across that? A, graphic novel.</p> <p>I: Mmm</p> <p>P: And she, she wouldn't read any of the books that I got her, I got that for myself and it just seemed to me that it – I mean that girls experience is different to Claire's but, some of the things reminded me of how Claire seemed. So I just mentioned to her "Look it's in</p>	<p>Supportive friends</p> <p>Dishonest Not eating or drinking No one believed her</p> <p>Closer to family Relational affects</p> <p>Through weakness compliant with help</p> <p>Suggested help Non-confrontational</p> <p>Declining help</p> <p>Mum suggested book</p>
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<p>my room” I am going to just turn the car on, so you may go on to speakerphone</p> <p>I: Ok, that’s alright.</p> <p>P: And she erm, and I just said “It’s in my room, if you want to read, read” and that’s the first time that she’d gone and looked at something and she said “Actually, some of that did resonate with me” So erm</p> <p>I: And if you came across other stuff, useful for her to read did you, was that the same “You’d say, I’ve come across this” if it would be useful?</p> <p>P: yeah yeah I did, and she mostly has said “No, I don’t want to do that”</p> <p>I: Yeah</p> <p>P: And so I’ve not pushed it. Because there is no point</p> <p>I: Yeah. Is there anything you would have done differently looking back?</p> <p>P: Differently, I might, erm, I don’t know, because I think the going private thing works for lots of people, but it didn’t work for Claire.</p> <p>I: yeah</p> <p>P: But, at the time, if I’d been a bit braver I might have waited to have gone down the NHS route, but then that would have been a different NHS route, because at the stage she was under 18.</p> <p>I: Yeah</p> <p>P: And it may have just – it may not have worked either. I think what we did do and I still don’t know if it’s right or wrong but we pushed her, we didn’t hang about in trying to get help. So I don’t know whether we panicked too much in the beginning, I honestly don’t know cause she was doing the cutting out of the drinking as well as the eating, so I guess we were forced into that. They did say at one of the meetings at – house, that that is an incredibly unusual presentation.</p>	<p>Mum suggested book Suggesting successful Daughter followed suggestion.</p> <p>Commonly refused help</p> <p>Private help didn’t work</p> <p>Fear drove seeking private therapy Waiting time a barrier to help</p> <p>Acted fast sought help quick</p> <p>Initial behaviours driven by panic/worry</p>
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<p>I: Mmm</p> <p>P: So erm, I honestly don't know. I think some of the things we did weren't exactly right but I wouldn't have done anything differently.</p> <p>I: Yeah, yeah. And has the experience changed your relationship with Claire. You talked about it changing as its gone along, but thinking back has things changed between when it started and now?</p> <p>P: yes oh yes I think so, I mean she's always been quite, well maybe she wasn't as confiding as I thought [laughs] but I think we are definitely very close now and again I would say because at the moment I would say touch wood, because she may go through this whole cycle again, but we're trying too, I guess we're learning, not to <i>push</i> her and we're []pause] so I guess that's the main thing, we're learning to let her set her own boundaries and make her own decisions and she is starting to want to look outwards a bit more, which is nice.</p> <p>I: Yeah, and what do you, with regards to people with anorexia, what do you perceive their fears are in getting support?</p> <p>P: Well I guess it's a fear that people will make them eat, and erm, and I think actually it's not so much a fear, but it was the case with Claire that she thought that she wasn't worth support.</p> <p>I: Mmm</p> <p>P: She felt she didn't deserve it and didn't deserve to have a normal happy life because she felt there was something wrong, with <i>her</i>.</p> <p>I: Mmm</p> <p>P: You know I remember one of the things she said most recent, admitted is that she takes up too much space</p> <p>I: Mmm</p> <p>P: Which is, you know really shocking, so I would say not so much a fear, but an unworthiness.</p>	<p>No regrets</p> <p>Relational affects Closer to family</p> <p>Stepping back – not pushing</p> <p>Letting daughter make own decisions Seeing change</p> <p>low self-worth a barrier to help</p> <p>low self-esteem</p> <p>Takes up too much space</p> <p>unworthiness</p>
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<p>I: ok, I've only got one more question for you. What would be your main piece of advice for someone who was trying to get an adult with anorexia to seek support?</p> <p>P: Erm, gosh, one bit of advice to get an adult to seek support [pause] err I guess, just [pause] ooh just trying to find the words to that, to be very gentle and caring and maybe to [pause] erm, to remember that they don't want to be like this and I think the thing that it took me, I didn't realise at the beginning, was how <i>starving</i> Claire was, You know that bad tempered and stuff, she was <i>starving</i> and so to understand that I guess that they, they're not in control of what's happening to them and you can't just pull yourself together.</p> <p>I: Mmm mmm</p> <p>P: So whilst you can't be inside someone's head, bullying them isn't going to help</p> <p>I: Yeah</p> <p>P. I would say that's probably the main- yeah it's not I would say it's fairly nebulous but just to be gentle, kind and understand that they don't want to be like this and it's not so much about wanting to be thin, it's about wanting – it's that feeling that they don't deserve to eat and to drink, and that gives you, I think that gives you a better perspective on why they're doing this bizarre thing to their bodies.</p> <p>I: Yeah, trying to understand it from a different perspective.</p> <p>P: And you know, you can get very cross with an anorexic [laughs] because you just think "Just eat it, for god's sake, just eat it!" but they can't.</p> <p>I: So being very understanding.</p> <p>P: yeah and a lot of it is the fear as well that once they start to eat they won't be able to stop and I think that's where a lot of people go on to become bulimic. You know, the association is that, that,</p>	<p>Be compassionate</p> <p>AN not a choice Understanding AN</p> <p>Person not in control of AN</p> <p>Bullying not helpful</p> <p>Compassion AN not about weight</p> <p>Low self-worth reason for behaviours Understanding of AN</p> <p>AN can be frustrating Frustrating for carer</p> <p>Fear of losing control</p>
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<p>they still don't deserve the food, but they can't stop themselves anymore</p> <p>I: The control has changed, the element of control.</p> <p>P: Yeah.</p> <p>I: I think that's all the questions I had to ask you, I wondered if there was anything I hadn't asked that you wanted to say at all?</p> <p>P: Erm anything I wanted to add. Just that the GP support was, terrible [laughs] and I'm <i>not</i> the only one to have experienced that, and in fact I wrote to our, to the first GP we saw, the woman GP, I wrote her a letter, you sent us away and this is what happened cause she had arranged to see us in 10 days time, and I said this is what happened in between those 10 days and my letter was basically saying, please be kinder to the next person that comes. She just sent me back the snottiest letter you had ever saw.</p> <p>I: Ooh that's a shame</p> <p>P: So I think the GP thing needs to change and you always think in this day and age it does, but that wasn't my experience, maybe that would be, be quite a big thing I mean she - even now when I go to the GP I look out for leaflets and things and I've never seen any.</p> <p>I: I guess that was your first port of call, so if it wasn't a good start.</p> <p>P: Yes exactly, absolutely, yeah, you don't know, what to do. And then that – I mean now I know about BEAT, the charity which I must admit I haven't found anything personally particularly useful to me but that doesn't mean it's not useful for other people.</p> <p>I: Yeah</p> <p>P: But I think we have been incredibly lucky, our friends have been really understanding and I've come across, stumbled across would be the word, some really excellent help</p> <p>I: Mmm</p>	<p>Low self-worth Lose control</p> <p>GP support terrible poor GP experience common</p> <p>GP needs to change</p> <p>No information at GP's Lack of information</p> <p>Don't know what to do Lost</p> <p>BEAT personally not useful</p> <p>Stumbled across good help Good help not obviously available</p>
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P: But It's not immediately, obviously available and you know another experience I had was when Michelle was really down, erm, someone suggested she should see a psychiatrist herself, so I found one locally who had a very expensive private clinic, and I took Michelle and this woman prescribed enough tranquillisers and whatever, to kill a horse and Michelle just needed someone to talk to, and that was shocking. And luckily my husbands a dentist and we looked it up in the formula when we got home and I said to Michelle "Try it for today" and she took literally one dose and she was literally unconscious for the next 24 hours and "I said right you don't take those again, you don't go back and see that woman, we'll do something else," and between – and with a lot of love and care and talking about stuff, Michelle touch wood seems, because Claire's settled and things to be easier at home and because we're making sure Michelle gets lots of attention, she seems to be doing ok, but if you don't know this stuff, you could just end up in this downward spiral, drugged and it'd be just horrible. And I think that where we're intelligent people, with resources but what if you're not.

I: Yeah, it's not clear, the help, what you're looking for, you can't find

P: And (inaudible) happens to families they're not aware – sorry what I find, I'm just going on and on, another friend of mine has a daughter who's ill and I said "Put me in touch with her" because I *know* how important it is, it's *really important* to talk to people (inaudible) because as lovely as everyone is, you can really talk to people afterwards.

I: Mmm people who've been through it

P: Yes, yes, so erm, it's the support groups and talking to people in similar situations, because you really – it's the people that are looking after the anorexic, aren't looking after themselves, and you

AN affects whole family  
Impact on family

Peer support  
Support groups helpful  
People shared  
experience helpful  
Carer self-care

can't really help the anorexic.	
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END OF INTERVIEW	
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## Poster

# The process of trying to facilitate an adult with anorexia to seek treatment

Samantha Cox<sup>1</sup>, Dr Mike Rennoldson<sup>2</sup>, Dr Anna Tickle<sup>2</sup>, Dr Faye Harrison Yuill<sup>3</sup>

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## Background

Anorexia nervosa is a physically, psychologically and socially disabling condition, with a high mortality rate. Whilst the potential illness burden is significant, individuals often do not seek help. Long delays in seeking treatment are related to poorer recovery outcomes.

Previous studies on help seeking in anorexia have focused on adolescents. There is a dearth of literature about problem disclosure and help seeking in adults with anorexia from the perspective of the significant other.

### Study Aims:

- To explore the role of significant others in problem disclosure
- To explore how significant others attempt to facilitate help seeking

## Method

A qualitative design was used. Individuals self-selected to participate. Participants took part in one semi-structured retrospective interview. Nine interviews were conducted via the telephone and one face to face. Data was analysed using thematic analysis following the guidelines by Braun & Clarke (2006).

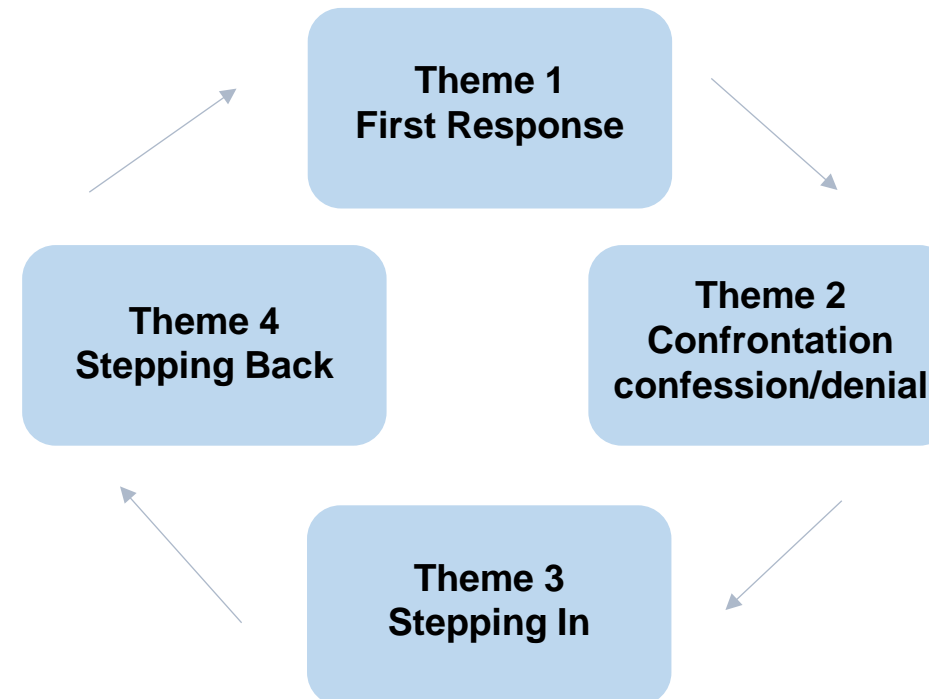
### Participants:

Ten women (partner, friend, parents) mean age 54 years self identified as a significant other who had tried to encourage an adult with anorexia to seek treatment.

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## Results



1. Many participants reported that they were not concerned by initial observed changes in the person's behaviour.
2. Participants reported that a specific event led them to confront the person with anorexia about their eating or weight.
3. Participants were active and persistent in supporting the person with anorexia to seek help. Participants offered informational, practical, emotional and cognitive support.
4. This was the key finding. Participants described how more direct approaches did not lead to a change in action and overtime they reported that they stepped back in their approach in trying to support the person.

## Discussion

### Implications

- There needs to be improved early detection of anorexia by GPs as this could prevent delays in the person with anorexia seeking treatment.
- Significant others of adults with anorexia may need to be encouraged to step back early on in their approach and be supported in doing this.
- Information about what to do to support a person with anorexia would benefit from being available in one source to delay the time it takes to find this information.

### Limitations

- Interviews were retrospective and this raises possible issues regarding the reliability of accounts which may have been subject to hindsight bias.
- Participants were largely recruited from the same source. Although this carer group covered a large geographical location in the UK it would have been useful to have heard some voices from other sources to compare experiences.

### Future research

- To investigate further how primary care reacts to help seeking.
- To explore the person with anorexia's experience of the stepping back approach.
- For carers to test the adequacy of information sources available for carers and explore preferences for information.

## **SSRI**

## Trent Doctorate in Clinical Psychology

**Summary of Service-Related Research and associated Impact (SSRI)**

Trainee(s)	Supervisor(s)	Placement	Cohort	Date Completed
Samantha Cox	Dr Kathy Huke	Thorneywood Adolescent Unit	2012	June 2015

**Research background and context**

Clinical psychologists use formulation with individuals, couples, families and groups. More recently, formulation has started to be used in multi-disciplinary teamwork (MDT) (Division of Clinical Psychology, 2011). Clinical psychologists might use formulation in MDT less formally, for example through discussions with colleagues or by commenting during team meetings (Christofides, Johnstone & Musa, 2011). Others have developed more structured ways, such as team formulation, where a shared formulation of a service user is constructed (Division of Clinical Psychology, 2011) that draws on the experience and skills of the whole team (Hollingworth & Johnstone, 2014).

Some of the benefits documented of formulation in teams include; staff-service user relationships, team working, increased understanding of service users and increasing psychological thinking of care plans (Craven-Staines, Dexter-Smith & Li, 2010).



### **The service**

Thorneywood Adolescent Unit is a 13 bed inpatient service for adolescents aged 12-18 years with mental health problems, who come to the unit for assessment and treatment. The team is a multidisciplinary team made up of a psychiatrist, psychologist, dietician, occupational therapist, an advocate, doctors, staff nurses and support workers.

### **Case formulation**

At Thorneywood Adolescent Unit, case team formulation is conducted twice a week on the unit, for 45 minutes, and is currently facilitated by the Clinical Psychologist. The team collaboratively decide on the day who they will discuss. This might be informed by someone that the team feel they would benefit from understanding more about, or a new admission. New admissions are discussed in case formulation within in two weeks of being admitted and revisited again after three months. An integrative psychological model is used, the content of which is based on the 5 p's model. This is completed on paper during the discussion.

### **Research aims**

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Psychologists in the service were keen to formally evaluate the team case formulation group to explore staffs experiences of attending. An email was sent to all of the staff team inviting them to attend a focus group. A pilot focus group was conducted to trial the questions. No changes were made from this and a second focus group was conducted. Data from both the pilot and second focus group was used in the analysis. Data was analysed using Thematic Analysis at the semantic level, following the guidelines of Braun & Clarke (2006).

In total, 13 staff took part in the evaluation; a mixture of staff nurses, support workers and doctors. Staff reported that they had

attended between 2 and 8 case formulation groups (mean= 4 groups) with one staff member having not attended any previously. The focus groups were facilitated by the trainee clinical psychologist and honorary psychology assistant.

### **What the research discovered**

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Five main themes were constructed from the data and are discussed below.

#### **Availability**

Some staff spoke about how due to shifts patterns it was difficult for all staff to be available to attend case formulation.

*"I think it's hard to get a good time, where everyone is free to come."*

Many staff agreed that there should be an equal opportunity for all staff to be able to attend, including bank shift staff.

*"Very fortunate to get outstanding bank...good to get them involved. Although we put them on obs, so we can go to case formulation."*

Staff also felt that a range of different professions attending case formulation, with different skills, is beneficial.

*"[Name removed] is back, so get the dietician involved. They can think of things in different ways. Their input would be helpful."*

#### **Communication**

One of the main issues raised by staff was that ideas generated about a patient in case formulation are insightful, but they reported difficulties in putting these into practice:

*"We do good work, but it goes nowhere."*

*"We can think of some ideas but then you can't obviously implement them until ward round and they get forgotten."*

Some staff spoke about how after case discussion, some staff members are allocated tasks, e.g. finding some more information about a patient's school history, but that there is currently no system in place to review whether these have been followed up.

*"We need a ward round format, an intervention plan to ensure that everything from case formulation is followed up."*

Many staff felt that case formulation generated useful ideas for helping them work with the patient, but that the information discussed is not documented in a place where all staff can access it easily. Currently, the formulation completed in the group, is held in the patient's paper file. However, staff felt that it needed to be documented elsewhere in order for more staff to be able to access it. Some ideas suggested were; discussing the formulation in ward round, documenting a summary on Rio, adding it to the weekly summary, or having a case formulation folder, where all the paper formulations are kept.

## **Flexibility**

The flexibility of case formulation, and deciding who to focus on at each group, was discussed positively, but also some limitations of this were highlighted. Staff felt that they could choose someone that they had found particularly complex to work with, did not have a lot of knowledge about, or someone whose behaviour they wanted to understand further.

However, flexibility on who to discuss was also seen as a limitation, as staff felt that some patients who were viewed as "less complex" did not get discussed as often:

*"[Staff name]: Do you think, do you think some people might be missed out from so some of the patients might not be talked about because they're..."*

*"[Staff name] Yeah, possibly...We normally focus on the ones where there's been more incidents or self-harm."*

### **Importance of MDT working**

This theme reflected how staff discussed the importance of MDT working and had two subthemes; safe practice and team skills.

Some staff also spoke about how discussing a patient as a team made them feel more supported in working with a complex patient.

*"It's reassuring as well to hear that other people are struggling to help a particular person as well, so we all kind of discuss who we want, who we think is struggling the most."*

#### Safe practice

Some staff spoke about how case formulation led to shared-decision making about the patient's care and shared responsibility. This echos some of the key points found in policies about young people; "Working together to safeguard children" (2015) and "The Children's Act" of 2004. Both these promote the team working together to support a young person, and the importance of communication in the team.

#### Team skills

Some staff reflected on how case discussion highlights the staff teams' skills and the positive work that the team does:

*"It highlights the skills set we've got."*

*"Realising what a great skills mix we have."*

*"It shows how we've worked well as a team, look how far we've come as a team with this person."*

## **Increased understanding of the patient and space for reflection**

Some staff commented that case formulation is a forum where they can share knowledge about the patient, learn from other staff members and generate discussion about intervention plans.

*"Can bring up new ideas, "God, we never thought about that" for example, engaging mum more."*

*"It's shared knowledge too as some people diff- lines of work so [staff name removed] sees things differently to how we might see things. So it's bringing those ideas together in a forum where you're all together rather than sort of in handover where it can get a bit disjointed."*

One staff member spoke about how having a better understanding of the patient meant that they could adapt their approach to meet the patient's needs:

*"[Patient name removed], I didn't have a full understanding of how low some of his cognitive abilities were and that when you said certain words to him he just didn't understand the words. Like, I mentioned about going to self-esteem group and he was like 'ahh it's stupid, it's stupid'. And then I sat down and said 'why is it stupid?' and thought about what [staff name removed] said about his cognitive ability and said 'do you know what self-esteem means?'. And he was like 'no, that's why I don't want to go'. And then I-realised that's why he wasn't going."*

*"Get everyone together and find out what others know. It's a wider discussion. Not knowing or knowing something can affect how you work with the patient."*

Many staff felt that case formulation was an opportunity to increase their understanding of the patient by making sense of their behaviour. Some staff commented that this was particularly useful if they had not had the chance to work with the patient yet.

*"When people think about behaviour, case formulation can help to understand the behaviour and the root cause to help understand. E.g. the sick role, deep discussions help you to understand, therefore more empathy, and better able to support. Rather than thinking it's just attention seeking."*

Many staff commented that case formulation provided them with a space to reflect on a patient. Some staff commented that this space allowed them to focus in-depth on one patient, others stated that the space could also be for debriefing, and to reflect on their practice.

*"You might have like up to an hour on one person, so you really pick apart what's gone on and you can have a good discussion. Whereas in ward round you've got two and a half hours to discuss 12 people."*

### **How the findings will be disseminated**

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The findings of the current service evaluation are to be disseminated at the next department meeting at Thorneywood Adolescent Unit and a copy of the report will be distributed to the managers at the Unit.

### **Service impact achieved by the research and future plans**

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The evaluation indicated the following:

- Staff report that they find case formulation beneficial.
- A summary of what is discussed from case formulation does need to be documented somewhere so that all staff can access it. Consideration is needed as to what is documented and where.

- Ideas generated in case formulation need to be put into practice. However, consideration is needed as to who would actions this. It might mean that a senior member of staff attends case formulation so that the patient's care plan can be updated? Or, ideas might be discussed and actioned in ward round?
- Some staff did not know when case formulation was on. Maybe there could be a poster on the unit, or it be mentioned in handover on the day, to remind staff.
- In the future, the evaluation might be repeated to evaluate the changes discussed above.
- Future plans might also include thinking about how team case formulation could be shared alongside diagnosis in ward round.

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**Trainee's Signature:**

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**Date:**

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**Supervisor's Signature:**

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**Date:**

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